LIVING WITH CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)

CENTRE FOR NEWFOUNDLAND STUDIES

TOTAL OF 10 PAGES ONLY
MAY BE XEROXED

(Without Author's Permission)

LISA M. KEEPING

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313/761-4700 800/521-0600

Living with Continuous Ambulatory Peritoneal Dialysis (CAPD)

by

Lisa M. Keeping

A thesis submitted to the School of Graduate Studies in partial fulfilment for the degree of Master of Nursing

School of Nursing

Memorial University of Newfoundland

St. John's, NF

September 8, 1997

National Library of Canada
Acquisitions and Bibliographic Services
395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale du Canada
Acquisitions et services bibliographiques
395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-25856-4

Canada

Dedicated to my parents, Walter
and Betty Keeping, and to my
grandfather, John Best.

ABSTRACT

The purpose of this study was to explore and describe the experience of living with continuous ambulatory peritoneal dialysis (CAPD) from the perspective of individuals who had used this form of renal replacement therapy. A large proportion of previous research on dialysis focused on hemodialysis with fewer studies on CAPD. Only four studies explored the dialysis experience from the perspective of the patient.

A phenomenological method of inquiry was used to investigate the experience of individuals living with this type of renal replacement therapy. An unstructured formal interview guide was used to obtain tape recorded interviews from 2 males and 6 females with CAPD. Each tape recorded interview was coded and transcribed into written text. Data analysis was conducted using van Manen's (1990) guidelines. Six themes were identified: (a) Maintaining hope: Cautioned optimism, (b) A different self: Presence of the catheter and dialysate, (c) The regimentation of life: Making an exchange every six hours, (d) Familiar intrusions: Growing accustomed to the procedure, (e) Being free: A paradoxical freedom, and (f) Sharing the responsibility: Importance of a support person. The essence of the experience was CAPD represented gain in the lives of individuals who had lost a great deal with end-stage renal disease - gain in the shadow of loss. Recommendations which arose from the findings of the study that had significance for nurses practicing in the field of dialysis were also discussed.

Acknowledgements

I wish to thank my thesis supervisor, Shirley Solberg, for her unending support, encouragement, and assistance throughout the writing of this thesis. I would also like to thank my committee members, Karen Parsons and Cheryl Harding, for their expertise, their critical reviews, challenging questions, and support. It was through your support and guidance that the research process for this thesis was made an enjoyable learning experience.

I would also like to thank my fellow graduate students for making this experience an enjoyable one. A special thank-you to Marilyn, Robyn, and Ann Marie, for your generous contributions of time for proof-reading and advice.

To the home dialysis nursing staff, Jocelyn, Lynn, and Debbie, thank-you for your patience and cooperation with the study. And finally, special thanks to the eight individuals who participated in this study. Without your generous giving of time and personal information, this study would not have been possible.

TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Although research and technological development have enabled us to understand and treat certain chronic diseases more effectively, there is no cure for many of these diseases in the immediate future (Carosella, 1993; Lancaster, 1988). Individuals with a chronic condition often have to cope with the symptoms of their disease as well as complex treatment regimens (Cheng, 1992). These individuals are faced with the tasks of trying to integrate the demands of their illness and treatment into their personal, family, social, and work lives (Carosella; Fuchs & Schreiber, 1988; Kyngas & Hentinen, 1995; McLaughlin & Zeeberg, 1993).

Changes in health care, together with the long-term course of many diseases, means self-care practices have become increasingly popular in managing the course of many chronic diseases (Goeppinger, Arthur, Baglioni, Brunk, & Brunner, 1989; McLaughlin & Zeeberg, 1993). Orem (1985) defines self-care as the activities initiated by individuals on their own behalf to maintain life, health, and general well-being. Self-care, the administration of a treatment regimen and management of symptoms associated with a chronic disease is often the responsibility of the person who has the disease and not of the health care team (Baker & Stern, 1993). Hence, it is important to understand the self-care practices of individuals with any type of long-term illness as they look after themselves at home on a continuing basis.

One chronic disease that involves a number of self-care behaviours is end-stage

renal disease (ESRD). Whether a person selects hemodialysis or continuous ambulatory peritoneal dialysis (CAPD) as the preferred method of renal replacement therapy, he/she is required to comply with a number of self-care practices to remain as healthy as possible (Baldree, Murphy, & Powers, 1982; Carosella, 1993; Fuchs & Schreiber, 1988; Killingsworth, 1993; Nichols & Springford, 1984).

Hemodialysis, the most common type of dialysis (Moncrief, Popovich, & Nolph, 1990), allows for the removal of toxins from the bloodstream by way of an artificial kidney machine (Christensen, Smith, Turner, Holman, & Gregory, 1990; Hoffart, 1989). CAPD, a more recent method of dialysis (Kelman, 1991), places increased responsibility for self-care practices on the affected individual. CAPD is usually performed in the privacy of the home with the individual responsible for initiation and maintenance of the procedure. This type of home-based dialysis, thus, requires the individual to take on the responsibility for his/her own care while allowing a greater opportunity for active involvement in self-care (Christensen et al.).

The management of ESRD with CAPD significantly alters everyday behaviours. Both the individual and family often adapt their lifestyles and daily routines to correspond with demands of the dialysis regimen (Killingsworth, 1993; Sensky, 1993). Yet we know little of what the experience of managing a complex treatment like CAPD is for individuals, how they see it as affecting their everyday living, or how and what they feel.

The remainder of this chapter contains the rationale, research question, and

purpose of the study. Chapter two is a review of selected literature. Chapter three is a discussion of phenomenology with special emphasis on the approach as outlined by van Manen (1990) and as employed in this study. Findings of the study are presented in chapter four. Chapter five is a discussion of the research findings. The final chapter contains limitations of the study and implications of the findings for nursing practice and research.

Rationale and Problem Statement

The impetus for this research comes from three main areas: my nursing practice, an increased number of patients using CAPD as a self-care modality, and the scarcity of research on the patient's perspective of being maintained on CAPD.

In my nursing practice I worked as a staff nurse with patients who were on CAPD. Throughout these interactions I observed that the CAPD procedure was a highly technical one and that the patient's expertise was acquired through a dialysis unit where they were taught the procedure. I noticed that once patients went home they were on their own and that they sometimes required assistance with performing their regimen. In many instances the patients relied on help from family members for assistance with completing a dialysis bag exchange but, whether they had assistance or not, they had to cope with this highly technical procedure involving themselves and they had to integrate it into their lives. These observations made me wonder what the experience was like for these individuals. I also felt that by understanding the

experience further there might be something nurses could do to aid these individuals in their adjustment with living with the regimen.

There are increased numbers of people depending on CAPD. Hemodialysis was the first mode of renal replacement therapy to be developed for ESRD and continues to be the most commonly used method with nearly 87% of patients with renal failure being maintained on hemodialysis worldwide (Moncrief et al., 1990). While only 13% of patients receive peritoneal dialysis it is becoming increasingly popular as more and more patients are now relying on this form of renal replacement therapy than ever before (Markell & Friedman, 1990; Martin, 1993).

In the home CAPD is the predominant form of self-care dialysis versus home hemodialysis and continuous cycling peritoneal dialysis (CCPD) (Brunier & McKeever, 1993; Moncrief et al., 1990; Pressly, 1995). In 1992, there were almost 70,000 patients maintained on CAPD throughout the world (Nissenson, 1994). At the end of December, 1994, the Canadian dialysis census listed 2854 people in Canada, and 78 in Newfoundland receiving CAPD (Fenton, 1996). Given these statistics, it is important that health professionals further their understanding of the experience of individuals living with CAPD. In order to effectively assist these patients, nurses need to understand the experience from the patient's perspective (Rittman, Northsea, Haussauer, Green, & Swanson, 1993).

Insight into the experience of living with CAPD may give nurses working with these patients a greater understanding of what patients confront and, therefore, a basis

on which to explore and perhaps develop nursing interventions. These interventions may enhance the quality of life and/or help with coping strategies. However, at the present time, most research into dialysis has focussed on hemodialysis. Research on CAPD has mainly had a quantitative focus and is limited in understanding the experience of living with this treatment from the patient's perspective.

This study will add to the current body of nursing knowledge by contributing to our understanding of how patients live with and manage complex treatment regimens. Although previous research has isolated factors influencing the ways in which people understand and conceptualize living with dialysis, there is still not a great amount of research that explores the experience from the perspective of the individual. This phenomenological study will provide an understanding into the experience of living with CAPD from the patient's perspective. This insight may help health professionals better understand the self-care behaviours of patients with CAPD. It may also sensitize nurses to develop appropriate teaching plans which will help these patients in managing their self-care. Often patients want to know what is involved in certain treatment regimens, how people manage these treatments, and what they might expect or how the treatments feel. The present study will explore this phenomenon. The research question that will be addressed in this study is: What is the experience like for an individual to live with CAPD?

Purpose of the Study

The purpose of this phenomenological study is to explore and describe the meaning of living with CAPD from the perspective of individuals who use this form of renal replacement therapy. There is an emphasis in the study on how individuals experience this particular treatment modality and how they incorporate it into their everyday lives.

CHAPTER 2

LITERATURE REVIEW

The presence of a chronic illness and the associated treatment usually means changes in the lifestyle and the quality of life of the person, as well as, chronic stress on the individual (Cheng, 1992; Sexton & Munro, 1988). Most research in the area of dialysis, apart from medical research on efficacy of different methods of dialysis and treatment outcomes, consists of quantitative studies on such aspects as compliance, stress and coping, family and patient adaptation to ESRD, and quality of life.

The majority of studies of individuals on dialysis focuses on hemodialysis and primarily on the negative consequences of the treatment regimen while not as much research has been done on CAPD. The purpose of this chapter is to provide a review of selected research under three main areas: dialysis and associated stressors; compliance with and adaptation to dialysis treatment; and the quality of life of individuals on dialysis. These areas were chosen because they are perceived to influence how one lives with dialysis (Killingsworth, 1993; Levenson & Glocheski, 1991; Rittman et al., 1993; Sensky, 1993). When available, research pertinent to CAPD is examined first followed by research on other types of dialysis.

Dialysis and the Associated Stressors

Four studies were identified that investigated the experience of being on

dialysis or living with renal failure from the patient's perspective (Beer, 1995; Jones & Preuett, 1986; Rittman et al., 1993; Snavely, 1980). A number of other researchers investigated stress and coping patterns across the different treatment modalities used for renal failure (Aoki & Muraoka, 1993; Baldree et al., 1982; Eichel, 1986; Fuchs & Schreiber, 1988; Gurklis & Menke, 1995; Kline, Burton, Kaplan De-Nour, & Bolley, 1985; Nichols & Springford, 1984).

Snavely (1980) conducted semi-structured interviews with 19 patients who had been instructed on self-care principles of CAPD. The purpose of the study was to look at the effectiveness and the long-term results of a home peritoneal dialysis training program after the implementation of a self-care philosophy. Self-care practices, defined as doing CAPD by one's self, were not maintained to the extent expected. All the patients eventually depended on someone at home to help them with dialysis. Additionally, they perceived themselves as disabled with regard to their ability to work and participate in family roles and felt depressed. Participants were involved in very few activities outside the home and their main social interaction was with their dialysis partner.

Jones and Preuett (1986) used a grounded theory methodology to investigate self-care activities and processes of 25 patients on hemodialysis. They identified four processes involved in self-care activities. The process of equalizing captured the ways patients learned to balance the demands of family, job, treatment times, finances, and body functions. Through the process of substituting participants were able to

exchange and replace desires and activities by trying out various replacements until they found adequate substitutes to meet their way of life and thus learn to juggle the competing demands for time, energy, and other desires. Withdrawing was the process that enabled participants to move away from events, people and ideas that were perceived as incompatible with their situation. They used activities such as avoiding discussions of the illness or not thinking of the future in this process. The last process, guarding, referred to maintaining vigilance over the body and the care given to them by health professionals. Monitoring the staff's work to ensure safety was viewed as an important self-care activity and part of the process of guarding.

Rittman et al. (1993) used a phenomenological approach to examine the lived experience of 6 patients on hemodialysis through the use of interviews held during dialysis sessions. An interpretative analysis identified three themes: taking on a new sense of being, maintaining hope, and dwelling in dialysis, and, as well, a constitutive pattern of "control: the meaning of technology". Participants viewed their illness experience as a normal part of their lives, described under the theme taking on a new sense of being. Changes related to renal failure and dialysis were incorporated into the usual course of everyday life. All participants maintained some source of hope for the future and this hope lessened the pain and disability associated with renal failure and sustained individuals in their daily living. The theme dwelling in dialysis represented living and being at home in the dialysis unit. The constitutive pattern of "control: the meaning of technology" was the way participants organized their thinking

and approach to life and how they saw technology controlling their bodily functions in order to maintain life.

Beer (1995) investigated patient's perception of changed body image while receiving dialysis and post-transplantation. Semi-structured interviews were held with 4 patients on hemodialysis, 4 patients with CAPD, and 4 patients who had received a transplant in order to explore the effects of different treatment modalities on the patient's perception of body image. Through content analysis Beer identified five categories: acceptance, quality of life, desire for body integrity, sexuality, and differences between genders. Acceptance involved the patient's need to accept changes in body image as well as have others accept alterations in appearance. Individuals who had had a transplant saw themselves as normal and wanted others to see them as normal. Those on dialysis disliked their access [fistula or peritoneal catheter] intensely but realized that without it they would die. Desire for body integrity involved how patients tried to conceal changes in body appearance. For those on hemodialysis the presence of the fistula meant having to wear long sleeve clothing while individuals using CAPD felt the enlarged abdomen presented a problem. Individuals with a transplant experienced problems associated with the physical effects of the immunosuppressant drugs. Quality of life was affected in a number of areas: work, changed relationships, physical effects, health, eating, holidays, and activities of daily living. Both patients with hemodialysis and CAPD felt that their chances for employment were minimal and that relationships with family, friends,

and children had changed. The two groups of individuals on dialysis also had to restrict their activities of daily living due to the presence of the access. No differences were identified by men and women in accepting an altered body appearance. Sexuality was affected as those with dialysis felt less attractive and desirable to their partners. Overall, patients with renal replacement therapy experienced numerous changes in coming to terms with their altered body image.

Stressors of Dialysis

One of the earlier studies investigating stress and coping in individuals with ESRD was done with a group of 35 patients on hemodialysis (Baldree et al., 1982). Coping was measured using the Jalowiec Coping Scale which had pre-established reliability and validity. Muscle cramps and fatigue were found to be the most frequently reported physiological stressors. Uncertainty about the future was also a top ranked stressor as was limitation of fluid. The most frequently reported problem-oriented coping method was maintaining control over the situation and the most common affective-oriented coping methods were hoping things would get better and prayer. A secondary finding of the study was that participants were more concerned with solving their problems than they were with reducing the emotional distress accompanying a stressful event.

Eichel (1986) investigated stress and coping in 30 patients on CAPD and made comparisons with those reported by Baldree et al. (1982) above. Data were

collected using two scales; a stress scale developed by Baldree et al. and the Jalowiec Coping Scale. CAPD participants reported less stress than hemodialysis participants, but both groups identified similar sources of stress. Both groups ranked among the top 10 stressors: fatigue, limitation of physical activity, muscle cramps, changes in body appearance, itching, and interference with their job. The author concluded that these stressors were related to the disease process of renal failure regardless of treatment modality. With regard to coping strategies, CAPD participants used less coping measures than did hemodialysis participants, which may have been related to their lower stress scores. Maintaining control, looking at the problem objectively, prayer, acceptance, hope, and thinking through different solutions were common coping strategies for the two groups.

In another study it was found that CAPD and hemodialysis patients experienced some of the same stressors and these were similar in number and intensity for the two types of dialysis (Fuchs & Schreiber, 1988). These researchers investigated 30 patients' perceptions of CAPD and hemodialysis stressors using the Stressor Assessment Scale. There were no statistically significant differences between the two groups on marital status, employment, education, and age. Fatigue, sleep disturbances, limitation of physical activity, itching, decreased income, decreased sex drive, and financial problems were among the top 10 stressors for both groups. Limitation of physical activity as the second greatest stressor for the patients on CAPD was consistent with that reported by Eichel (1986). Loss or change of employment,

decreased value in oneself, and decreased interest in hobbies were also ranked as very important. These authors concurred with Eichel that there are many similar stressors in both hemodialysis and CAPD and that the stressors are secondary to the illness and not the treatment modality.

Kline et al. (1985) constructed a questionnaire and compared reports of stress with 53 patients on CAPD and 143 patients on hemodialysis. The most common stressor for both groups was physical weakness. Individuals on CAPD rated fluid restrictions, sleep disturbances, headaches, and decreased sexual functioning lower than did individuals on hemodialysis. Overall, those with CAPD reported a lower frequency and severity of stressful situations than individuals on hemodialysis. The authors did not, however, provide information on the reliability and validity of the questionnaire.

In another study Aoki and Muraoka (1993) investigated stressors and adaptation to daily life with 56 patients using CAPD. Data were collected using a scale devised for the purposes of the study. Items rated as high CAPD stressors included the frequency of bag exchanges, itch, fatigue, anxiety about the future, and restriction of physical activities. It was also found that the awareness of CAPD stressors increased according to an individual's situation particularly whether one had a job or not. Other findings included: 1) absence of an occupation had an impact on the perception of stressors, 2) the degree of anxiety about the future and work related stressors were high for those over 60 years of age, 3) items related to work stressors

were higher for males while items related to body image were higher for females, and 4) there was a qualitative difference in stressor cognition between patients with a history of CAPD for less than 3 months and those on the regimen for longer. There were also reported differences in the degree of cognition among patients with regard to work difficulties and the absence of familial support.

Gurklis and Menke (1995) used a descriptive survey combining qualitative and quantitative aspects to investigate the perceptions of stressors, coping methods, and social support of patients on long-term hemodialysis. A structured interview schedule with open-ended questions guided the interview. Additionally, patients were asked to complete the Hemodialysis Stressor Scale, the Jalowiec Coping Scale, and the Personal Resource Questionnaire, all of which had established reliability and validity. Subjects were able to maintain control through involvement in decisions relating to their care, monitoring their bodies' response to treatment, taking medications to relieve symptoms, reporting problems to health care providers, seeking information, following fluid and diet restrictions, and having learned their limitations so as not to risk their lives. Many subjects stated that they relied on others for help, and discussed problems with family, friends, and health professionals. Spouses or significant others, adult children, siblings, and dialysis nursing staff were the most frequently identified support persons, however several subjects worried about being a burden and wanted to maintain reciprocity in their relationships.

Compliance with and Adaptation to Dialysis

Two areas that have been studied in relation to dialysis are compliance with the regimen and adaptation to dialysis. Various researchers have examined factors associated with compliance or adaption to one of the different forms of dialysis.

Compliance with Dialysis

Compliance is defined as "the extent to which a person's behaviour coincides with medical health advice" (Hussey & Gilliland, 1989, p. 605). Even though researchers have made a number of attempts to isolate discrete variables that might influence compliance behaviours with the dietary, medication, and fluid restrictions of the hemodialysis regimen (Christensen, Smith, Turner, Holman, Gregory, & Rich, 1992; Cummings, Becker, Kirscht, & Levin, 1982; O'Brien, 1990; Poll & Kaplan DeNour, 1980; Schneider, Friend, Whitaker, & Wadhwa, 1991; Weed-Collins & Hogan, 1989), relatively few studies have looked at variables which might affect compliance with the CAPD regimen (Wolcott, Maida, Diamond, & Nissenson, 1986). Research into the compliance behaviour of individuals who are on CAPD may help us understand some of their perceived barriers to maintaining themselves on dialysis, some of the challenges faced, and factors which might influence their compliance.

Locus of control, a personality construct, has been investigated by several researchers (Parker, 1983; Poll & Kaplan DeNour, 1980; Schneider et al., 1991; Williams, Stephens, McKnight, & Dodd, 1991). Patients on hemodialysis who had an

internal locus of control (ILOC) were found to be more compliant with treatment regimens than those with an external locus of control (ELOC), indicating that an ELOC may not be adaptive in terms of adjustment to dialysis (Poll & Kaplan De-Nour, 1980; Williams et al., 1991). Poll and Kaplan De-Nour used a convenience sample of 30 men and 10 women and investigated the adaptive function of an ILOC. Compliance was assessed using a 5-point Likert scale and locus of control using Rotter's (1966) locus of control questionnaire. Compliance with dietary restrictions for individuals with an ILOC were far better than for those with an ELOC.

In another study investigators found that the presence of both an ILOC and supportive family environment predicted adherence of patients on hemodialysis to an exercise program (Williams et al., 1991). Specific background information was obtained on 40 participants and each person's locus of control was evaluated. However, the researchers did not provide details on the measures used to assess locus of control. Adherence was determined by the degree of participation in an exercise program. The adherent group more frequently reported an ILOC; 68% of the adherents had an ILOC. Additionally, the adherent group (75%) had support from family that encouraged exercise progress whereas only 25% of the non-adherent patients reported family support.

Contrary to these findings, Schneider et al. (1991) in a study of fluid noncompliance in patients on hemodialysis found that locus of control was not a significant predictor of compliant behaviour. In a sample of 50 subjects a number of

cognitive and emotional variables (i.e., depression, and anxiety) were assessed in relation to compliance. Locus of control was determined on the Locus of Control of Behaviour Scale and compliance by four questions designed to assess perceptions about fluid compliance. It was demonstrated that locus of control was not significantly related to past compliance, self-efficacy, and perceived success of past compliance. Path analysis revealed that locus of control was not a good predictor of compliant behaviour with hemodialysis regimens.

How patients feel about their illness can also influence compliance behaviour with the hemodialysis regimen. Cheek (1982) investigated the feelings of 27 patients on hemodialysis towards their treatment regimen and the effects on compliance. Data were collected using the Response to Illness Questionnaire and results indicated that individuals holding more positive feelings towards their illness were more compliant with regimen requirements than those holding negative feelings. Responses of the compliant group reflected acceptance of the illness, not blaming others, acceptance of responsibility for own care, ability to control anxiety, and recognition of gain in some instances with the illness. Cheek concluded that assessment of a patient's attitude can help predict compliance behaviour with the hemodialysis regimen.

Social support has been another factor that researchers have investigated in relation to compliance behaviour with ESRD regimens. Hume (1984) conducted research into the dietary compliance of individuals on long-term intermittent peritoneal dialysis and found support for the positive influence of a supportive family

environment. Hume devised an interview schedule and administered it to 15 males and 10 females who were receiving long-term intermittent peritoneal dialysis. Not only did patient's perceptions of severity of illness influence compliance, but family support and interactions with health care team members also enhanced adherence to dietary regimens. This research added to an understanding of the relationship between family support and compliance to dietary restrictions in long-term intermittent peritoneal dialysis. However, the small sample size and lack of reported reliability and validity of the measurement instrument decreased the credibility of results.

Another study by Christensen et al. (1992) also investigated adherence behaviours in patients on both home and in-centre hemodialysis related to family support and physical impairment. The sample consisted of 55 patients receiving in-centre and 26 receiving home hemodialysis. Data were collected using three scales, all of which had reported reliability and validity measures. Individuals holding perceptions of a more supportive family environment exhibited significantly more favourable adherence to fluid restrictions than did those reporting less family support. The researchers did acknowledge that the 57% response rate for the sample decreased the ability to generalize results. The researchers speculated that non-responders may have been more representative of individuals who were less compliant with fluid and dietary intake.

In a nine year longitudinal non-experimental design by O'Brien (1990) it was found that secondary system member support (professional caregivers) was more

important than primary group member support (family and kin) to adjustment. A standardized interview schedule measured social support from family and professional caregivers and another scale assessed compliance. Data were collected at three points in time and qualitative interviews were conducted during the last data collection period. Despite loss of subjects due to death over the 9 year period, O'Brien witnessed an unexpected finding - participants who died earliest demonstrated the highest compliance and those who survived to 9 years had the lowest reported compliance to the hemodialysis regimen. O'Brien accounted for the unexpected result with the concept of reasoned compliance in that patients on dialysis learn to manipulate the system in regard to dietary, fluid, and medication requirements of the regimen. Additionally, for patients of lower socioeconomic standing professional caregiver support was more strongly correlated with compliance than that of primary group member support. This finding could be attributed to the fact that families of patients who are of lower socioeconomic class and are on hemodialysis have more immediate problems than planning for specific compliance with health care regimens.

The results of another study were contradictory to those of previous studies. Cummings et al. (1982) found little association between support given by family members and compliance to hemodialysis regimens. In a sample of 50% males and females (n=116) compliance with medication and dietary regimens was assessed retrospectively from information on patient's charts and patient's self-reports. The data analysis procedures were not clearly stated, but the researchers concluded that

information on compliant behaviour from medical charts and patient's self-report measures of compliance were weakly correlated. The measure of support from family and friends was not related in any way to the patient's compliance behaviours.

Other researchers have attempted to investigate whether or not level of knowledge has an influence on compliance behaviours of individuals on dialysis (Chan & Greene, 1994; Christensen, Smith, Turner, & Cundick, 1994; Everett et al., 1993; Prowant et al., 1989; Weed-Collins & Hogan, 1989). Prowant et al. found that knowledge about hemodialysis and CAPD regimens enhanced compliant self-care behaviours. These researchers devised and implemented a phosphorus education program and measured knowledge using a pre-test and post-test to 21 patients on hemodialysis and 14 patients on CAPD. All subjects completed a pre-test prior to receiving the devised educational program. Patients were not informed that they would have a post-test or that future monitoring of their serum phosphorus level after a 6 week interval would occur. Overall, it was found that the CAPD group did have more of a decrease in serum phosphorus levels than did the hemodialysis group. The researchers concluded that the significant improvement in the CAPD group's scores did represent real learning as there were behavioural changes that caused a lower phosphorus level. Despite the presence of a positive relationship between knowledge and compliant self-care behaviours in the CAPD group, there were a number of confounding variables that might have limited credibility of the results.

Christensen et al. (1994) assessed the interactive effects of treatment modality

and patient characteristics on adherence and depression with 52 patients on hemodialysis and 34 patients on CAPD. Coping styles, depression and adherence were all assessed using a variety of reliable and valid instruments. An individual's tendency to seek information about treatment did not necessary imply that he/she would become involved in his/her own care. Higher levels of "information vigilance", i.e., monitoring threat or health-relevant information, were associated with dietary adherence for patients with CAPD.

Studies by Everett et al. (1993) and Weed-Collins and Hogan (1989) demonstrated an opposite relationship between level of knowledge and compliance behaviour. Everett et al. used a sample of 141 patients receiving hemodialysis and investigated factors that contributed to noncompliance with fluid restrictions in the hemodialysis regimen. Fluid noncompliance was determined using scales that measured psychological, sociodemographic, and medical variables. The major predictors of noncompliance were being male, young, having an external locus of control, and a high educational level. Education and knowledge alone were not sufficient for achieving compliance to fluid restrictions.

Weed-Collins and Hogan (1989) investigated the relationship between knowledge and phosphate-binding medication and adherence with the medication regimen. A questionnaire developed by Cummings et al. (1982) to measure compliance with patients on hemodialysis was modified to assess knowledge and health beliefs. Even though the reliability and validity of the modified instrument

were not reported, results indicated that knowledge was not related to compliance behaviours. Similar to findings of Cummings et al., the most common barrier to taking medication was forgetfulness and being away from home, not knowledge about medication.

Adaptation to CAPD

In the earliest study located Brown et al. (1974) studied some of the factors associated with adjustment to home dialysis. The study consisted of open-ended interviews with 11 patients. Four areas were identified which distinguished individuals who adjusted well to dialysis from individuals who adjusted poorly: sources of financial support, effectiveness of the patient's helper, the impact of change on the patient's physical and mental state, and the prominence that dialysis played in the patient's daily life. Well adjusted subjects did not stress financial problems or the importance of these problems in their lives, minimized their losses and focused on the capabilities they still retained, and developed a sense of independence that allowed them to lead active lives. In contrast those who were poorly adjusted were unable to overcome these challenges. The assistance of a helper for the patient played an important role in fostering adjustment; those with greater assistance from their helper adjusted better. Although this study provides insight into the factors which might promote adjustment to dialysis there are a number of problems with the study design. The authors did not clearly describe whether it was CAPD or home hemodialysis they

investigated, incorrectly labelled the study experimental, had no definition for adjustment, and did not describe the data analysis procedure.

A number of other research studies have addressed the psychological adaptation of patients on CAPD (Gonsalves-Ebrahim, Gulledge, & Miga, 1982; Lindsay, 1982; Schlebusch, Botha, & Bosch, 1984; Shurr, Roy, & Atcherson, 1984; Whittaker, 1984). Several authors advise that when selecting individuals for CAPD, it is important to choose persons who are highly motivated, mentally competent for understanding the procedures, believe in the importance of compliance, and have a system of support at home (Borgeson, 1982; Oreopoulos & Khanna, 1982; Perras & Zappacosta, 1981). In a study by Gonsalves-Ebrahim et al. data were gathered on 46 patients on CAPD to assess psychological factors in predicting adherence with the regimen. Data were collected through information supplied in the patient's history, mental status examination, and family interviews. Six factors were identified as important for predicting overall adjustment and adherence with the regimen: mood and ability to test reality, cognitive function, body image, ability to handle crisis and stressful situations, personality structure, and support and acceptance of the regimen by relatives. These results indicated that careful evaluation and selection of candidates for CAPD are necessary to ensure better adaptation to regimen requirements.

Lindsay (1982) collected data on 178 hemodialysis, 80 CAPD, and 25 intermittent peritoneal dialysis patients to assess the influences of physiological and psychological dimensions on adjustment. Data were collected through structured

interviews with patients and spouses, chart abstractions, and individual clinical assessments by team members. In the short-term both CAPD and hemodialysis were equally stressful in psychological, social, and economic terms. Clinically significant results were found in a number of areas. Patients with CAPD required less training time which had economic implications for the dialysis unit in lower costs and for the patient who is returning to work. There was a higher incidence of hospitalization for those on CAPD over the age of 40, and the regimen also interfered with employment and participation in household chores. Finally, individuals on CAPD reported less sexual distress than patients receiving hemodialysis. However, those who were less than 45 years and had high levels of anxiety and increased diastolic blood pressure were less likely to cope with the regimen.

Whittaker (1984) used a descriptive study and identified psychosocial factors which discriminated between patients who adjusted and those who did not. In a sample of 25 patients two scales were used to assess psychological factors. Patients who adjusted and stayed on CAPD tended to be more venturesome, experimenting, and self-sufficient than those who did not continue with CAPD. These individuals were more adaptable to change and manifested control of their emotions and behaviour. The less well-adjusted person tended to be more conservative, perhaps indicating that even though the cautious personality type might be better equipped to adhere to CAPD, they might have difficulty integrating the treatment regimen into their lifestyle. The authors did acknowledge that the small sample size limited the

usefulness and ability to generalize findings to other patients on CAPD. Reliability measures were reported for the two scales but for the Family Environment Scale only face validity was reported.

Shurr et al. (1984) used a systematic interview schedule and interviewed 10 women and 22 men on CAPD regarding their physical health, feelings about dialysis, mental health, and sexuality. Twenty-eight percent of the patients had worries about CAPD as a treatment. Several patients reported it had been difficult to adjust to the CAPD routine and others reported feeling pain while doing the bag exchanges. Most reported acceptance of CAPD as a necessary treatment with some experiencing difficulty adjusting to the changes in their lives that CAPD required. There was also evidence of stress and monotony in the daily use of CAPD.

Quality of Life

Even though many modern day treatment regimens allow for continuation of life, the ability to extend life is not the only measure to evaluate (Cheng, 1992; Fox et al, 1991). Treatments which slow the progression of many diseases can have both physical and psychological implications for the affected individual. As a result quality of life of individuals on long-term treatments has become a focus rather than just considering morbidity and mortality factors.

Quality of life is an outcome measure that has been poorly assessed in patients on long-term peritoneal dialysis (Nissenson, 1994). Because of this, important factors

that contribute to outcome on various forms of peritoneal dialysis are unknown. The major problem when looking at this issue has been the absence of a standard definition that might cover all aspects of quality of life. Researchers do agree, however, that it is a highly complex concept with no agreed upon operational definition (Levenson & Glocheski, 1991; Molzahn, 1991; Nissenson; Sensky, 1993). There is some consensus that the concept does involve variables such as physical, social, and psychological functioning, family life, financial security, house, and job satisfaction (Fox et al., 1991) and the best way to measure quality of life is by using a multidimensional instrument (Fox et al.; Molzahn). Hence, researchers, in attempts to investigate quality of life in renal replacement therapies, have used a variety of instruments. The general problem with these instruments has been that most were not designed to look at issues pertaining to ESRD, and more specifically certain treatment regimens. This has led to speculation that the scales most frequently used such as the Karnovsky Index, the Sickness Impact Profile, and the Psychosocial Adjustment to Illness Scale, might have been less sensitive than those designed especially for use in renal disease (Sensky).

Research concerning the quality of life of patients on various methods of renal replacement therapy is extensive. Several studies have attempted to investigate quality of life from the patient's perspective (Ahlmen, 1990; Hoothay, DeStefano, Leary, & Foley-Hartel, 1990; Mohzahn, 1991), while others have compared the impact of various forms of treatment modalities (Auer et al., 1990; Bihl, Ferrans, & Powers, 1988; Bremer, McCauley, Wrona, & Johnson, 1989; Chubon, 1986; DeVecchi et at.,

1994; Evans et al., 1985; Muthny & Koch, 1991; Simmons & Abress, 1990; Simmons, Anderson, & Kamstra, 1984; Tucker, Ziller, Smith, Mars, & Coons, 1991; Wolcott & Nissensen, 1988). Most of these comparisons have been based on evidence from quantitative studies, but several studies did include subjective views of patients on certain measurement scales.

Molzahn (1991) contended that because different measures had been used to evaluate quality of life, the most basic philosophical question "What constitutes a good life?" had never been addressed. She used the Aristotelian-Thomistic philosophical theory of the good life to investigate quality of life in patients on home hemodialysis. This philosophical theory is based on the premise that there are seven real goods: goods of the body, mind, character, political, personal association, social, and economic, and all are necessary if an individual is to have a good life. Using a descriptive qualitative design she conducted a series of semi-structured interviews with participants to determine whether or not patients on home hemodialysis possessed each type of real good. Two card sort tasks were used for ranking the importance of each type of real good. Content analysis of the transcribed interviews demonstrated that most patients possessed goods of personal association and economic goods. Common problems of lack of health, vigour, freedom of action, pleasurable feelings, and free time were reported by more than half of the participants. Participants also identified excellent knowledge and understanding of their disease and treatment as an indicator of goods of the mind. Another finding was that all possessed goods of character and

that personal relationships were very important to participants. With regard to political goods, patients reported lack of freedom of action due to restrictions imposed by the illness and treatment. Molzahn found that attainment of one type of good such as health through dialysis, affected the attainment of other goods, such as restriction of activities. The participants all perceived goods of the body and personal association to be most important.

Ahlmen (1990) investigated the concept of quality of life from the perspective of patients on renal replacement therapy. Mailed surveys were sent to 104 patients either receiving hemodialysis, CAPD, or having a renal transplant. The survey was comprised of two open-ended questions for which participants had to compose descriptive written answers. Despite the low response rate, patients on renal replacement therapy most often used physical-medical aspects alone, or in combination with, social aspects, to define quality of life. Individuals with renal transplants exhibited a higher quality of life in terms of well-being than did both the hemodialysis and CAPD groups. Physical-medical factors dominated among measures to improve quality of life and social factors were of more importance to those on dialysis than to those with a kidney transplant.

Hoothay et al. (1990) studied 12 diabetic patients who were on hemodialysis in order to assess perceptions of quality of life. Seven females and 5 males who volunteered to participate were interviewed using Cantril's Self-Anchoring Striving Scale (SASS) along with two open-ended questions. Content analysis identified seven

underlying themes: hope for the future, living day-to-day, fear, acceptance, sadness, anger, and happiness. Hope for the future was the predominant theme, however many of the hopes of participants lacked a realistic base. Even though most feared the future because of worsening health and loss of social support, they chose to avoid thinking about it by having positive thoughts. Participants expressed acceptance or resignation of a lifestyle that an out of control health status had imposed on them.

Comparisons of quality of life across treatment modalities has sometimes found CAPD to be superior to hemodialysis, but inferior to home hemodialysis and renal transplantation (Auer et al., 1990; Evans et al., 1985; Kutner, Brogan, & Kutner, 1986; Simmons & Abress, 1990; Simmons et al., 1984; Wolcott & Nissenson, 1988). A study by Simmons et al. compared quality of life of patients on CAPD, hemodialysis, and those with a renal transplant. They defined quality of life as involving physical, emotional, and social well-being. Questionnaires used for the study contained both closed and open-ended questions. Results of this mail survey indicated that patients on CAPD showed a more favourable adjustment than patients on hemodialysis. Those on CAPD admitted to less uremic symptoms and activity difficulties, demonstrated higher ratings of health, self-esteem, and general well-being, and had better vocational rehabilitation. Patients on CAPD also indicated less unhappiness with their treatment regimen. Those who had received renal transplants however, did better than both the hemodialysis and CAPD group on all measures.

Evans et al. (1985) assessed quality of life of 859 patients receiving CAPD,

hemodialysis, or a renal transplant to determine whether objective and subjective measures of quality of life were influenced by treatment or other variables. Data were collected through patient interviews, medical records, health professionals familiar with the patients, and patient's completion of questionnaires. A larger percentage of the transplant recipients were able to function at near normal levels and could hold employment better than could individuals on all three types of dialysis. Patients on home hemodialysis demonstrated the highest quality of life along subjective measures of life satisfaction, well-being, and psychological affect when compared to other methods of dialysis. Patients on long-term CAPD had a better perceived health status, a higher rating of well-being, and greater life satisfaction than patients on hemodialysis. Additionally, the quality of life of transplant recipients compared well with the general population, but patients on dialysis did not work or function at the same level as people in the general population.

In another study 33 matched pairs of patients, either on hemodialysis or CAPD recruited from three dialysis programs were studied to assess their current medical, psychological, and social status (Wolcott & Nissenson, 1988). Data were collected by participant's completion of questionnaires, information from medical charts, and nurse's and doctor's completion of various instruments. Participants were matched on criteria of sex, age, diabetic status, time on dialysis, race, and years of education. Patients on CAPD reported lower illness and treatment regimen stress scores, nonsignificant lower mood disturbances scores, and had a higher quality of life.

Those on CAPD also participated in more community activities, had better relationships with physicians and other patients on dialysis, and were more likely to be active in a vocation. Participants on the two treatment modalities did not show any differences in self-esteem or health locus of control. Method of dialysis treatment likely has an effect on the quality of life of dialysis patients, and CAPD was generally superior to hemodialysis regarding medical, psychological and social variables. The researchers did recognize that in deliberately excluding patients on dialysis from the study who were in poor physical and psychological health, they limited the ability to generalize findings to all patients receiving dialysis.

A multicentre study in Germany involving 11 hemodialysis, CAPD, and renal transplant sites was undertaken to investigate various complaints patients had across treatment modalities, as well as patient satisfaction with different components of life (Muthny & Koch, 1991). Quality of life was assessed through a clinical questionnaire that covered measures of emotional well-being, vocational situation, family life, and leisure activities. As many as 30% of the patients on hemodialysis were not satisfied with life in general, as compared to 17% of the CAPD group and 5% of the renal transplant group. Overall, all three groups were mainly dissatisfied with their physical performance, sex life, vocational, and financial situation. Family life and interpersonal relationships were the areas least affected by illness and treatment. There were a number of somatic, psychosomatic, and psychological complaints present among all three treatment groups but the types of complaints differed widely across groups.

Individuals on CAPD complained mostly of muscle cramps, restless legs, blood pressure problems, restlessness/nervousness, and fear of the future. Similarly, DeVecchi et al. (1994) investigated well-being in ESRD patients and found that individuals on CAPD reported more free time, more freedom, better overall well-being, and less worry with their treatment regimen than individuals on hemodialysis.

Other researchers have reported no differences in the quality of life for individuals on hemodialysis and CAPD (Bihl et al., 1988; DeVecchi et al., 1994; Tucker et al., 1991). Bihl et al. compared stressors and quality of life of patients on hemodialysis and those on CAPD and found no significant differences between the two groups. A sample of 18 matched pairs comprised the study population. Findings did not indicate that patients on CAPD enjoyed an improved general well-being and greater life satisfaction when they switched from hemodialysis. In addition, there were no reported differences in the amount of stress experienced or the perceived health status of the two groups. For those on CAPD problematic stressors were uncertainty about the future and limits on time and place for vacations. Individuals on hemodialysis ranked fatigue and boredom with the routine as the greatest stressors. Despite the inability to generalize findings due to convenience sampling, results did raise speculation about the belief that patients on CAPD have a higher quality of life than those on hemodialysis.

Similarly, Tucker et al. (1991) investigated variables such as dietary adherence, hope, martial status, emotional support, participation in social, recreational,

and work activities, self-esteem, education, and well-being in a group of patients on hemodialysis versus those receiving CAPD. Data were collected using a number of reliable and valid instruments that assessed quality of life along the dimensions of physical, emotional, and psychological well-being. Even though patients on CAPD engaged in significantly more social and recreational activity than did patients on hemodialysis, no statistically significant differences in quality of life variables due to treatment modality or demographic variables were found.

Summary of Literature

Research into a person's experience of living with CAPD is limited, although we have knowledge of various aspects of that experience. Research into the aspects of this experience was grouped under three main headings: dialysis and the associated stressors, compliance with and adaptation to dialysis, and quality of life for those on dialysis. Most of the research focuses on hemodialysis as opposed to CAPD, or other forms of dialysis, and a good deal of the research is quantitative. While providing important insights into selected aspects of the experience the predominance of quantitative research makes it difficult to assess how many of the relevant factors have been identified and to appreciate fully what the person's experience is like.

The literature on dialysis and associated stressors does indicate that individuals living with CAPD not only have physical complications as a result of ESRD and associated treatments but also have numerous psychological and social problems.

Much of this research focuses on the stress as a result of the disease process and coping with the illness rather than on the treatment modality, or conflates the two. While both the disease and treatment are closely interrelated, it is important to distinguish between them in order to capture the experience of living with dialysis as opposed to living with a chronic illness if we are to understand how patients handle complex treatment regimens.

Most research was done on compliance with and adaptation to dialysis. Many of these studies examined the personality construct, locus of control, as a factor in influencing compliance, some looked at the importance of social support, while others studied the importance of knowledge about various treatment regimens. While the results of these studies are inconclusive, knowledge and social support appear to be important to compliance and adaptation.

Quality of life studies are important to people with chronic illnesses especially as newer treatment modalities are developed which permit the prolongation of life. Although there are a number of limitations in the research in this area because of the difficulty of defining quality of life, a number of studies have given us important insights into dialysis as a treatment modality. Therefore, it is the intent of this study to increase understanding of the experience of living with CAPD so ultimately improvements might be made to the care delivered to this group of individuals through a greater understanding of what it is like for a person to live with CAPD.

CHAPTER 3

METHODOLOGY AND METHODS

This chapter is divided into two main sections. The first section is a brief overview of the methodology used in the study. The second section is a detailed description of the particular methods employed. The methods are discussed under the headings of: participants, recruitment of participants, data collection, data analysis, credibility, and ethical considerations.

Methodology

The methodology used for studying the experience of living with CAPD was phenomenology as described by van Manen (1990). van Manen conceptualizes phenomenology as the study of the lifeworld. People's experiences are researched in order that a deeper understanding of phenomena, as they are experienced, is obtained. The aim of attaining deep "insightful descriptions" (p.9) comes only from reflecting on the experience as it is lived. van Manen believes that it is only through reflection that insight evolves. According to van Manen when investigating any experience as it is lived, a researcher is always concentrating on the meaning of lived experience. The aim of philosophical inquiry is to borrow people's experiences in order that a richer, deeper, and more insightful understanding might be obtained of the phenomenon in its entirety.

van Manen (1990) acknowledges as a core concept the idea of essences. The

discovery of the essence of an experience is the ultimate purpose of phenomenological philosophy. Phenomenology strives to disclose the structures or internal meanings as they are lived by the people experiencing them. To uncover the essence of an experience, or the "whatness" that makes an experience what it is, van Manen refers to the concept of "bracketing" or the premise that essences can only be truly discovered by setting aside one's own beliefs in order to focus on the structures of the world as they are lived by someone else. Bracketing is thus a methodological attempt to portray the reality of informants. Swanson-Kauffman and Schonwald (1988) suggests this process allows the researcher to reduce his/her beliefs about the phenomena being studied.

Another key concept of van Manen (1990) is intentionality. This refers to the oneness that human beings have with their surroundings. Intentionality "indicates the inseparable connectedness of the human being to the world" (p.181). It does not conceptualize the mind, body, and world as separate entities. It is only through the conscious act of the mind that human beings are aware of their inseparable being in the world. Therefore, by consciously reflecting on one's particular experience of being in the world, phenomenology serves to truly know "one's very nature" (p.5).

According to van Manen (1990), phenomenological research consists of an interplay among the following six research activities:

1. identification of a phenomenon which interests us and commits us to the world,

2. investigation of experiences as lived rather than as conceptualized,

3. reflection on essential themes that characterize phenomena,

4. description of the phenomenon through writing and re-writing,

5. maintenance of a strong and oriented relation to the phenomenon, and

6. consideration of parts and wholes to balance the research.

Turning to lived experience, "is the starting point and end point of phenomenological research" (van Manen, 1990, p.36). The aim of phenomenology is to textually capture the description of the phenomenon such that those living the act will relive the experience through reading and reflecting upon the written description. The researcher in the act of becoming embedded in the lived world of a participant maintains a strong orientation to the phenomenon. In order to accomplish this enmeshment, or commitment of oneself to a phenomenon, the researcher needs to be truly interested and find personal meaning in reliving with a participant a certain experience. It is at this point the researcher needs to bracket any pre-existing suppositions he/she may have with regard to the phenomenon. Even though this means disregarding the existence of the thing and concentrating on the whatness, what is disregarded or bracketed is not denied. Any preconceptions are temporarily set aside and attention is focussed only on what remains (Bochenski, 1965).

Observations and literary materials are two methods of gathering information about experiences, but the interview process is the main way. It is through personal interviews that experiences are shared and the interviewer can actually enter into the

lifeworld of the participant. Continual questioning during an interview is not always necessary as silence may be just as helpful in allowing time for reflection (van Manen, 1990).

Once data is collected the researcher must take time to reflect on essential themes that characterize a phenomenon (van Manen, 1990). van Manen metaphorically describes a theme as "knots in the webs of experiences around which certain lived experiences are spun and thus lived through as meaningful wholes" (p.90). A theme essentially describes or captures some aspect of the structure of the phenomenon under investigation. When interview transcripts are analysed and thematic concepts identified, the researcher seeks validation for his/her conceptualizations of the experience by going back to the roots of knowledge itself and/or collaboration with a seminar group. When one goes back to the roots of knowledge or the actual participants, the researcher and interviewee collaborate to decide if what has been interpreted is an accurate description of the phenomenon. Collaborative analysis with seminar groups aids the researcher in generating "deeper insights and understanding" (p.100) into the lived experience of individuals.

It is only after completing the thematic analysis that one can begin to materialize thoughts and feelings through the art of writing and re-writing. Writing fixes thought on paper and it is this act which allows the researcher to grapple with and discover the internal structures of experience (van Manen, 1990). According to van Manen phenomenology, as a research methodology, would not be what it is

without the art of writing. The transformation of experience to thoughts, words, and then written text is the core of the phenomenological research process. "Writing creates a distance between ourselves and the world whereby the subjectivities of daily experience become the object of our reflective awareness" (p.127). van Manen also believes that to write in the phenomenological sense is to re-write. Arriving at the essence of an experience does not come from a lone writing attempt. It is only through the act of repetitive re-writing that a researcher can reflect and come to a greater understanding to reveal depth and insight into the experience.

Throughout the continual process of writing and re-writing it is essential that the researcher strive to remain oriented to the phenomenon under study. The researcher may find it easy to become sidetracked with inconsequential details (van Manen, 1990). Throughout the process of attempting to uncover underlying meaning structures, it is also necessary to keep in perspective the total experience and to understand how each part of the experience contributes to the total.

Methods

For this study the researcher interviewed and analysed data from 6 women and 2 men who had chosen CAPD as their method of renal replacement therapy. This experience of working with the participants and the data in the study aided in gaining an insight into what it is like to live with this type of dialysis.

Participants

The study participants came from the pool of individuals in Newfoundland who were using CAPD as their method of renal replacement therapy. Men and women 19 years of age and over who were mentally competent and could describe their experience to the researcher were eligible for inclusion in the study. Individuals who had been on CAPD for at least 6 months were the target of recruitment as this is the length of time it usually takes for an individual to adjust to the realities of the dialysis regimen (Sorrels, Mullins-Blackson, & Moncrief, 1982). Since all individuals could speak English no one was excluded from the study. In total there were 8 participants.

Recruitment of Participants

After ethical approval by a Human Investigation Committee the Assistant Nursing Director of Medical-Surgical areas and the Medical Director of a peritoneal dialysis unit in an urban hospital were initially contacted to obtain permission to access the peritoneal dialysis patient roster. Upon obtaining permission from both sources (see Appendix A & B) the researcher approached three peritoneal dialysis teaching nurses for their consent to assist in recruiting participants. The nature of the study was explained to the nurses and their cooperation was requested in identifying and initially contacting potential participants.

A total of 8 potential participants were originally contacted by one of the three teaching nurses to seek approval for the researcher to contact patients on CAPD and to

provide them with further details. All 8 individuals contacted agreed to participate in the study but one became seriously ill and required extensive hospitalization before the interview date. A replacement participant was then recruited by a teaching nurse and this person agreed to participate. When the researcher made telephone contact with each potential participant she explained the study and established an interview time.

Data Collection

Interviews were conducted by the researcher at a time which was convenient for participants. Seven individuals preferred to be interviewed in their homes while one requested the interview be conducted during an appointment at the home dialysis unit. All participants were provided with a copy of the formal consent (see Appendix C) and the details of the study were discussed with each participant. There was a third person present prior to the commencement of each interview in order to obtain a witnessed consent.

Each interview lasted approximately 45 to 90 minutes and all participants agreed to the audiotaping of the interviews. Each participant was assured that all audiotapes would be destroyed once data analysis was completed. They were also informed that a second or third interview might be requested for clarification of data approximately 3 months after initial interviews. A total of six re-interviews were done; two were completed by telephone and four were in the homes of participants. One participant died prior to being contacted for a second interview and the last

participant was not re-interviewed.

Data were collected using an unstructured formal interview process. At times, interviews were guided by an interview guide (see Appendix D) to which the researcher resorted in the event that a participant requested or needed prodding. According to Swanson-Kauffman and Schonwald (1988) the interview schedule serves only as a prompting devise, "The types of questions included are meant to be provocative and a creative means of getting informants to talk about their own experience of the phenomenon" (p.100). The interview schedule was referred to on a number of occasions as participants were sometimes unsure of what to talk about next. Participants were told at the beginning of the interview that the researcher was interested in their thoughts, feelings, and ideas concerning life with CAPD. Individuals were encouraged to talk about anything that would help the researcher understand the experience.

After the initial interviews had been transcribed and beginning identification of themes made, which took approximately three months, second interviews were held. The purpose of the second interviews were to get clarification, explore some aspects of CAPD in greater depth, and to provide an opportunity for validation of possible themes that were identified from the first interviews. At this time the participants, if they had not already described the experience of their first bag exchange, were asked such questions as "I was wondering what you thought the first time you ever did a bag exchange?". Alternatively they might have been asked to confirm a preliminary

theme. "I know you said before [previous interview] that when your kidneys failed, you experienced a lot of changes and loss in your life. But looking at the dialysis itself [focus of study] would you consider it a gain?".

The second interviews ranged between 15 to 30 minutes. The brevity of these interviews was explained by the fact that many of the participants claimed to have exhausted their description of the experience and did not have much to add to the data.

Data Analysis

Upon completion of each audiotaped session the researcher immediately transcribed the interview into written text. This process allowed the researcher to become familiar with the data and to get involved in what participants were saying. Each written text was then transcribed into typed text and this process again allowed the researcher to gain further understanding of the data. Finally, audiotapes were reviewed with the typed text to ensure accuracy of data transcriptions.

Once the first eight interviews were transcribed the researcher identified initial themes from the data. The transcripts were analysed in accordance with the highlighting approach as identified by van Manen (1990). With this method of analysis the researcher selected and highlighted segments of dialogue that she felt were reflective of the experience of living with CAPD.

These highlighted segments were read with the researcher coming to an understanding of what the participants were saying, what meaning it might have for

them and how to capture the meaning thematically. When the verbatim text was finally organized into themes the researcher discussed with her supervisor the themes that she had identified. After this, themes were further developed and presented to the thesis supervisory committee. Audiotaping of the committee's discussion helped the researcher to reflect on the discussion and draw further understanding from any comments regarding the development of themes. This meeting also served as a form of validation as the researcher was able to confirm with the committee her thoughts and feelings on what participants were saying.

Six re-interviews were completed after meeting with committee members. No new themes were identified from these interviews but they did help in developing the themes more fully. A number of re-writes of the themes occurred and each draft was given to committee members for their input and validation. Confirmation that findings were complete occurred when all members agreed that themes, as they were written, were an adequate description of the participant's experience.

Credibility

To ensure the researcher's interpretation of findings was an adequate reflection of each participant's experience, the researcher undertook several activities to establish credibility. According to van Manen (1990) findings of qualitative data are credible only when they are returned to participants to judge the accuracy of interpretations. In this instance re-interviewing of subjects and discussing the first interview material

gave the researcher opportunity to discuss with each participant the themes she identified from the data. The researcher felt confident of the truthfulness of findings when participants agreed that the interpretations were indeed what they were saying (Sandelowski, 1986). In several instances participants chose to expand on findings, thus assuring the researcher that she had captured more fully the experience of living with CAPD.

Credibility of the findings was again attained with the researcher's submissions of the written text of the interviews and themes to committee members. One member of the thesis committee was selected because of her extensive clinical work with CAPD. Members were given ample time to read and reflect upon transcripts and to offer suggestions or question the researcher's analysis and interpretation. Collaboration with committee members aided in enriching the discovery of meaning embedded in the text and confirming themes identified. The ability of committee members to follow the decision trail (Sandelowski, 1986) of the researcher further added credibility to the results.

Ethical Considerations

Approval for the study was obtained from the Human Investigation Committee at Memorial University of Newfoundland (see Appendix E). As well, written permission to access the CAPD patient roster at the hospital was granted from the Medical Director of Peritoneal Dialysis and the Assistant Nursing Director of Medical-

Surgical areas. Following approval from the Human Investigation Committee approval for the study was obtained from the Health Care Corporation Medical Advisory Board (see Appendix F). Individuals who met the inclusion criteria were initially contacted by one of the three peritoneal dialysis teaching nurses in order to obtain permission for the researcher to contact them.

Informed consent was obtained before the beginning of the first interview. The researcher adhered to guidelines for witnessed consent in all instances to confirm that the study had been adequately explained and that it was the participant's signature. The purpose of the study, procedures to collect data, and time required were explained at this time. The researcher ensured that a copy of informed consent was left with each participant. Individuals were informed of safeguards to preserve confidentiality such as not including identifying information in the findings. Participants were also informed again that they could withdraw from the study at any time.

Codes were used on the transcribed interviews and, therefore, participants could not be identified in any way. Participants were told that all identifying information would be destroyed once data analysis was complete. The transcripts were kept in a secure place that only the researcher could access. Participants were also told that although they would not benefit directly, knowledge gained from the research would possibly be of help to other patients with CAPD in the future.

The last ethical issue addressed concerned the risks of participating in the research. If a person became upset during the interview the researcher reminded the

person that the session could be terminated immediately. This did happen during the first interview but the participant chose to continue as she felt this was the first opportunity she had had to talk about her feelings. The participant expressed her gratitude about being given an opportunity to express "pent up" emotions. The researcher did ensure that the participant was in a stable emotional state at the conclusion of the interview. The individual was then encouraged to share her thoughts and feelings with her family and/or physician.

CHAPTER 4

FINDINGS

This chapter is divided into three sections. In order to have a better understanding of the participant's experiences, a brief overview of each participant is presented in section one. Section two consists of the themes identified and section three describes the essence of the experience.

Overview of Participants

A total of 8 participants were interviewed. They ranged in age between 25 and 73 years of age and included 2 men and 6 women. The first participant interviewed was a 67 year old woman who lived at home with her elderly husband. She had been diagnosed with ESRD 16 months prior to the interview and was maintained on CAPD for the first 7 months after diagnosis. This participant had no other problems with her health and currently had her name on the renal transplant list. In the meantime, she had decided to try CCPD as her method of renal replacement therapy since a problem with a disc in her back made the continuous presence of dialysate in her abdomen very painful.

The second woman was a 33 year old single parent. Her primary diagnosis was ESRD with no other associated illnesses. She was diagnosed with renal failure 20 months prior to participation in the study and had been on CAPD since starting on dialysis. For this woman the diagnosis was sudden and therefore she had to

immediately incorporate the condition and CAPD regimen into her life. She lived approximately a ½ hour drive from the home dialysis centre and stayed alone with her teenage daughter. She had her name on the renal transplant list but had mixed emotions regarding a transplant as her mother died while undergoing the same surgery.

The third participant was a 54 year old man whose primary diagnosis was diabetes. ESRD and blindness were secondary to this condition. This man lived at home in an urban centre with his wife. Both of his adult children lived away from home and because he had extensive loss of sight his wife assumed most responsibility for his care. However, due to his inability to work, the participant's wife had taken a job that took her away from home for at least 8 hours every day. This participant had been on dialysis for 2 years; the first 6 months on hemodialysis and the remaining time on CAPD. This man will be maintained permanently on dialysis as he was not a suitable candidate for a kidney transplant.

Another participant, a 51 year old woman, was on dialysis for the second time. She lived in an urban centre with her husband and teenage daughter. She had other adult children who lived away from home. This participant was diagnosed with ESRD 14 years prior to participation in the study. Renal failure was her primary diagnosis and she could not pinpoint a cause for her illness. She lived with hemodialysis for the first 4 years after diagnosis, during which time the family had to uproot and relocate to an urban centre for dialysis services. After 4 years this participant received a kidney transplant from a close relative and the transplant remained functional for 7

years. With the need to go back on dialysis again, this participant chose CAPD and had successfully used this method for the last 23 months. She was currently awaiting a second kidney transplant.

The fifth participant, a 73 year old woman, had been on CAPD for the last 20 months. This woman had previously received hemodialysis for 8 years, during which time she experienced a number of problems with access lines. She admitted that living with CAPD posed no problem for her as two of her daughters had assumed total responsibility for her care. This participant widowed, moved from her own home at the time of commencement of CAPD as she felt her physical condition prohibited her from doing the dialysis herself. She was confined to her home most of the time and home visits were made by different professional services to care for her needs. She had hoped that CAPD would continue to keep her alive, however, she died prior to the second interview.

The sixth participant was a 67 year old man who had been on CAPD for 2 years. He chose CAPD for renal replacement as this form of dialysis allowed him to remain living in his home, 900 kilometres from the CAPD unit. Renal failure for this participant was secondary to diabetes and hypertension, both of which were diagnosed 2 years prior to ESRD. He lived at home with his wife and was primarily responsible for his own care. He had decided to remain on CAPD indefinitely, but during the interview sessions he expressed a change in attitude towards kidney transplantation.

The seventh participant, a 25 year old woman, had been married 5 months

when she learned she would need dialysis. She had never really been well but had never been diagnosed with any type of illness. A diagnosis of ESRD, secondary to hypertension, came as a surprise. She chose CAPD as it allowed her to live in her newly built home, located 900 kilometres from the home dialysis unit. She was primarily responsible for her own dialysis but felt her husband was there to perform the regimen if ever she needed him. This participant was currently awaiting a kidney transplant, even though she was extremely fearful of the surgery. She had been on CAPD for 12 months and it had been her only method of renal replacement therapy.

The final participant was a 70 year old woman who lived at home with her 78 year old husband. They lived 900 kilometres from the home dialysis unit. The participant had been on CAPD 14 months, during which time she had a daughter-in-law come from next door everyday to assist with her regimen. She required this assistance as she could not read or write and needed help with recording weight, temperature, and blood pressure readings. Since going on CAPD she had learned to record readings for her dialysis record. This woman had a long history of kidney stones and was aware for years of impending kidney failure.

Thematic Analysis

The following is a presentation of themes that were identified through the interview process with the 8 participants. A total of six themes were identified from the data and the order in which they are presented does not represent order of

importance but they all address an important aspect of living with CAPD.

Maintaining hope: Cautioned optimism

The ability of participants to maintain some source of hope for the future was a theme which occurred throughout all the interviews. Hope is defined in the Oxford English Dictionary (1978) as "expectation and desire" (p.405) and aptly describes what the participants felt. However, it was not a hope based on a false notion of the seriousness of their disease condition - ESRD. Rather, it was tinged with the reality of what may happen so it involved a "caution" with the optimism that having hope can produce. All the participants spoke of hope for the future in some way or other and CAPD was important in maintaining that hope:

> You lost your kidney, but there's still a way you can live you know.

As shown in the overview of the participants in the study, some saw CAPD as a means to an end, getting a kidney transplant. They were assessed as suitable candidates for a transplant and were receiving CAPD until a kidney became available. For these men and women CAPD was important as a temporary arrangement, a "stepping stone":

> But we got a chance now where I can get a kidney and go back to a normal life.

While maintaining hope that CAPD would support them until they received a kidney for transplant each individual also cautiously acknowledged that their treatment could be permanent:

> But it could be worse, and this [dialysis] could be it. This could be your last chance. It could have to last you a lifetime.

For those not assessed as suitable candidates for a kidney transplant because of other complications, CAPD was an end in itself. These individuals hoped that CAPD would last indefinitely and continue to keep them alive. They realized they depended on dialysis so they saw CAPD as a source of hope for the long-term. In these instances participants maintained hope in the "duration" of CAPD. They were thankful for the treatment and recognized that it was responsible for maintaining their life and keeping them healthy. CAPD was a means of buying time for a longer life, but again a caution was noted in their reflection:

> But now I'm not sure how long that [CAPD] lasts though. I guess it can last for a long time though, depending on how well you look after yourself.

> The dialysis is going really well you know, perfect. How long its going to last I don't know. Its been two years now since I've been on it.

Generally participants were positive about being on CAPD, choosing to talk about the treatment in a hopeful way:

> I suppose I can look at it this way. I can be thankful I'm still healthy in another sense. There's nothing else wrong with me, just my kidneys, right.

While they were positive and spoke about CAPD and how it helped them to maintain hope for the future, this hope was definitely coloured by what I termed "cautioned optimism" because of some of the potential problems that could develop while on CAPD which could make it impossible for them to continue. One of the common problems with CAPD is an infection in the peritoneal cavity so every time they drained their dialysate they had to carefully inspect each bag for any sign of infection. They were constantly aware that the dialysate could contain a definite sign of an impending infection. As a result, they cautiously inspected each bag of drained dialysate and hoped that no signs of an infection were present. They realized that if signs of an infection were present then their continued maintenance on this method of dialysis could possibly be jeopardized. Even though they lived with the hope that they would complete each bag exchange without difficulty, they remained cautious as they

never knew what to expect:

> Everytime you let a bag out you're looking for, looking at the colour to make sure that's all right you know.

> With this [CAPD] my dear you don't know how quick things can change.

Some participants maintained a sense of hope for their future by viewing their illness as life-threatening, and not terminal. These individuals believed that for diseases such as cancer there was no treatment available that could prolong life indefinitely but such was not the case for them. Even though they knew that dialysis was not a cure for kidney disease, it was a treatment that provided hope for the continuation of their life. Everyone recognized that CAPD was not a guarantee for staying well, yet it was a source of hope that allowed them to live another day:

> But its better than cancer or something that's going to kill you. There are options.

> I mean anybody could have cancer or anything wrong, like two or three things wrong, and comparing this to that, I mean, I got it knocked.

Others maintained a sense of hope when they compared themselves with those who had successfully used CAPD. In these comparisons the participants saw what they hoped could possibly be the same for themselves. Many spoke of the people they knew who had lived for years on CAPD and had experienced very few complications. Despite knowing people who had successfully used CAPD the participants still remained cautious as they knew that other problems related to kidney failure could occur and reduce their chances of success:

> . . . I had 3 options and I thought that my sister-in-law had been on it for about 10 years and she was doing grand. I thought the bags would be all right for me too.

A different self: Presence of the catheter and dialysate

The participants saw themselves and their lives differently as a result of both ESRD and being on CAPD. It was evident in this theme how intertwined the disease process and the treatment were. They did realize the seriousness of their disease and had difficulty in accepting the fact that they were sick:

> . . . its hard getting used to the idea that you're sick and you'll never be well again.

They had to get used to the change in their health status, a change they recognized as permanent even if they underwent a transplant. A transplant would allow them to have a more normal life and mean that they didn't have to be on CAPD or hemodialysis, but they were under no illusions that this would solve everything for them:

> Even if I do have a transplant or not, then I'll never be the same again. With a transplant I'll still be looking at a lot of problems.

Apart from incorporating the new meaning of health into their lives two aspects of CAPD seemed to be important in how they saw themselves. A second theme was identified which related to the presence of the peritoneal catheter and dialysate and how it resulted in the way individuals viewed themselves. The presence of the peritoneal catheter dangling from the abdomen was stressful for some as they no longer felt the same about their physical appearance. Viewing the catheter as a foreign object in the body was clearly expressed by one participant:

> When I got that [catheter] first I just felt like pulling it off and throwing it away you know. It was just like, I don't know, like that's not suppose to be there.

The presence of the catheter in the body had to be incorporated into how each person saw him/herself. Over time, most became used to the catheter as part of their body and were no longer conscious that it was there. They were able to forget about the presence of the catheter:

> Oh, I don't even know that's [catheter] there. First now, first when I came home and was sleeping, I was a bit nervous that I would roll over on it. But now I sleeps on it and everything. Don't even know its there.

> But she [nurse] said, "you'll get used to it after a while". And you do. You get used to it. Now I twists that [catheter] all around, flops it all around.

Having 2000 mls of dialysate continuously remain in the abdomen also caused some participants to see themselves differently. Everyone had to adjust to the feeling of having this amount of fluid in their abdomen, and as a result, many expressed feeling bloated or full. As long as the dialysate was present in the body many individuals felt that their bodies had changed physically:

> When the fluid is in your stomach all day long, your clothes don't fit right. As you get more and more solution into you that, you're body is never the same. I says that I'm going around 9 months pregnant all the time.

Even though the two male participants described how the dialysate in their abdomens made them feel full, they did not seem to have as much difficulty with viewing their bodies differently as did several females. They accepted more easily the bigger bellies that they both mentioned but they were not as concerned about how they might look to others. One woman in particular had a difficult time accepting the changes she perceived in her physical appearance. She had such a difficult time accepting the changes in herself that this affected her ability to enter a new relationship. She did not feel that someone would be able to accept the physical changes in her body that had resulted from CAPD. She felt that having to perform the regimen and the presence of the indwelling catheter inhibited her from even going out to meet someone new:

> I'm a single person you know, and I suppose you know it affects relationships. It really does. So basically, I've been more or less, keeping to myself. Like I don't like to go out or anything like that. I don't. So I just don't feel like it. Because the way I am, I'm not interested anymore.

The same person commented on her feelings regarding the intimacy of such relationships. The presence of the catheter was definitely an inhibiting factor:

> I can't tell you about sex. Because I haven't had no one in my life since then [CAPD]. So I would imagine it would be hard right. I wouldn't anyway. If I did, not with a catheter in anyway.

Even though the participants commented on changes in their physical appearance because of the catheter and the continuous presence of dialysate in their abdomen, for most of them it was not an overriding concern. They recognized changes for what they were, differences.

The regimentation of life: Making an exchange every 6 hours

The way in which the CAPD regimen resulted in each individual's life being regimented was a third theme identified in the interviews. Individuals on CAPD are expected and taught to do a bag exchange every six hours in order to maintain a continuous exchange rate. This means that they had to put a regimen in place in order to accommodate the treatment into their lives. To plan their regimen individuals had to take into account the number of [bag] exchanges they needed within a day:

> So you try to get your 4 bags in within 24 hours. So you have to do it [dialysis] pretty much every 6 hours.

Even though doing a bag exchange approximately every 6 hours sounds relatively uncomplicated, changes participants were required to make in order to incorporate their treatment regimens with other aspects of daily living were not of a minor nature. Since we do not necessarily structure days into 6 hour sections, all the participants described how, since starting CAPD, the structure of their lives had changed a great deal:

> Like it makes a lot of changes in your life. Say about ninety percent of your life changes.

For some, this was a very abrupt change, a rupture in how they organized and lived their daily lives. Daily patterns which had developed over a lifetime had to be changed very quickly. There was no lead-in time to gradually adjust to the change:

> It was like my life changed in a couple of hours, right. And it hasn't been the same since. No it hasn't. . . . Like I say, nothing has been the same since.
>
> So everything like, just fell apart. That was it, it was like a big explosion and everything was all gone.

What seemed to change most for these individuals as I explored this aspect of living with CAPD with them was their daily activities and, more importantly, how they had to consciously think about these activities and plan ahead:

> I do have to plan. It was not like I could just go ahead and do something without thinking about it.

Everyone, of course, has to do some planning ahead, to check to see if they have other commitments, but generally they have some flexibility in scheduling, for example, in deciding on something as simple as a trip to the shopping mall or a meal with friends, one can decide to go at a moment's notice. This was not so for the participants in this study as they described the impact of CAPD on their lives:

> Well your lifestyle changes right away. You can't get up and go when you like. Like you know, if I was invited out to supper, I would have to do the bag change at five instead of six and then I would have to leave and come home early.

> Like you, I find that, you know, you don't, I guess you don't have the freedom you used to have, I suppose. Like I say, you got to be home. Actually you're doing it [CAPD] four times a day. Its like every time you turn around, you're

doing it.

Being on CAPD even changed whether one went out or not. Participants sometimes made a decision on the basis of how that fit with the regimen. The activity was then shaped by when it was time to do their bag exchange. As participants explained:

> If I do have to go out, I just do what I have to do and I know I gotta be home at this time.

> I find that if I go anywhere, I got to rush back and do my dialysis.

For others it was the consequences of the regimentation such as the inconvenience of this imposed treatment regimen. They felt they had little time to fit in their social activities between treatments and as a consequence just stayed at home:

> . . . it was inconvenient because you had to be home you know every four hours to do your change.

Additionally, many of our lives are linked with those of other family members as we plan activities together and engage in some negotiation over scheduling.

However, this is not the case for individuals who are on CAPD and it is their regimen which dictates scheduling for other family members as well as for themselves. In exploring with the participants their experiences many of them mentioned how various family members had to adjust their activities to fit with CAPD. They certainly recognized the effects on other family members:

> . . . it [CAPD] changes your husband's life a lot too.

> Well he [husband] took it hard at first. Cause, I mean, we can't have children now. But that's something we can live with. But it did bother us at first.

Many of the participants described how they had to interrupt their participation in special family events to return to their homes to perform a bag exchange at a scheduled time. One woman recounted how she had to leave a family christening and go home. Others described how it was difficult to plan events with friends because they had to factor in when they were scheduled for the procedure:

> Another thing with the bags, you had to be home four times a day. And like even if we were invited out to supper or something, you don't know what time you could go.

> And like say if my friends call me and ask me to go here and there, I have to say, well boy I can't. I gotta do my dialysis in an hour or something like that.

Depending on their lifestyle prior to CAPD, adaptation to the regimen was more difficult for some than others. For individuals who liked to stay up late at night and/or get up early in the morning it was less of an adjustment. However, staying up until 12 o'clock at night or getting up at 7 or 8 o'clock in the morning proved to be a real hardship for many. They no longer had the luxury of staying in bed late some mornings - something many of us without the same commitment can take for granted:

> By the time night-time comes around, and by 10 o'clock, I'm beat out. I want to go to bed but I can't because I got to stay up and do my dialysis. If I'm out, like I got to stop whatever I'm doing and come back. I can only put it off so long.

> You couldn't go to bed when you like. You had to stay up to do it and you had to get up early. And I liked to sleep in. I had to wake up early in the morning to do my bag exchange.

Familiar intrusions: Growing accustomed to the procedure

CAPD is an invasive procedure. It requires the person to instill 2000 mls of dialysate in their abdominal cavity and let it remain there for about 6 hours. Even before this takes place the person has to have a catheter surgically implanted in their abdomen on a semi-permanent basis. It is hard to imagine doing/having this done to your own body. A fourth theme identified dealt with the way in which all individuals eventually incorporated the CAPD regimen into their daily lives and made it a part of their normal routines. All the participants could remember back to their first reaction to the procedure. They were afraid of the idea of having to perform the procedure as they did not know what to expect. Even though they were told what to expect prior to the procedure it was difficult to envision what it would feel like or how they would look:

> It was frightening starting off though, when you really didn't know what you were in for.

> . . . it frightened me because when I went in I was expecting to see all this tubing hanging out.

For the lay person performing technical medical procedures have somewhat of a mystic associated with them and doing these procedures on themselves adds to the complexity. The participants felt that the procedures were too complex to deal with

on their own, however, they knew they had to be able to perform CAPD before they could go home on this treatment. One of their fears was that they would not be able to learn to do the exchanges:

> That's one thing [CAPD] I never thought I'd learn how to do. Because that's what I told the nurses.
>
> I said, "My dear [nurse] I'll never get through this". Because there's so much to do, there's a lot of worries there.

One of the most prevalent concerns of the participants was that they would feel the dialysate going into their peritoneal cavity. It was hard to imagine that the fluid could be instilled and they wouldn't feel anything:

> And I was afraid I was going to feel it going in and that. And I was going to be cramping up and stuff like that. But I mean, it wasn't like that at all, right.

All the participants could recall vividly the first time the dialysate was instilled in their abdomen. They all gave a vivid description of this experience. One of the aspects of the first CAPD instillation that still amazed the participants was really how little they were aware of the dialysate flowing in their abdominal cavity and how painless the

procedure really was. This was certainly in contrast to what they had expected the procedure to be like:

> I remember the first time - when she [nurse] put the first drop in. She only put in so much at a time. When I found out what it was like, I said, "put it all in so I won't have to go back on the machine no more".
>
> And I turned my head and I said, "okay, I'm ready now". And I was saying to myself, "I wonder what she's [nurse] doing?". And then I looked and the bag was half empty, gone, and I didn't even know it.

Having the procedure done in the protective atmosphere of the hospital or under the watchful eye of the dialysis nurse was one thing, but having to perform the procedure at home by oneself was another. All the participants were scared when they thought about assuming responsibility for their exchanges when they first went home:

> And I tell you now, when I think about it, I was pretty nerved up about doing it. After all, it wasn't like you were in the hospital with one of the girls [nurses] there looking over your shoulder. Even though they showed me what to do, when I did it myself, I was on my own. I used to dread for the time to come to have to do my dialysis.

> Well, my dear, I fair shook. I was that shaky I didn't think I'd ever get it done. But like when you're on your own you don't have much choice but to do it. Everything is up to you.

Besides being fearful that they would be unable to complete CAPD on their own, the participants were also afraid of handling their catheter. They realized that the catheter was vitally important to performing CAPD, and so they were scared of possibly injuring it, or themselves, when manipulating it. These fears made them extremely cautious when they first cared for the catheter on their own:

> Cause I was nervous handling it [catheter], right. Cause to me it was going to fall out and I was going to hurt it and stuff.

However, feelings of self-doubt and anxiety were gradually replaced with feelings of self-confidence as everyone repeatedly cared for the catheter and performed CAPD without experiencing any problems. Over time everyone became more self-assured in their ability to do the regimen and they no longer worried about every single step in the procedure. There was a marked contrast in the way that these individuals felt in the beginning and how they eventually felt:

> I think though after I did the dialysis and needles a few times and everything seemed to be working out all right, I didn't mind so much then.

> First I didn't think I would be able to do it. It took me about a week to get comfortable with it. Like first when I started I used to be really particular. I would have to be really exact with everything. But now I don't mind it so much. I'm a lot quicker now.

Having 2000 mls of solution added to one's body is a feeling that most individuals cannot ever begin to understand. However, for these individuals this experience rapidly became commonplace as the dialysate had to remain in their abdomen in order for them to feel well and be able to carry out their day-to-day activities. Even though some of them felt bloated by the solution, for the most part they described no feeling associated with its presence in their abdomen:

> Well, at first I felt like I was all full of it [fluid]. But now I don't mind it. Well, I was expecting to feel that fluid flopping around in there or whatever. But its nothing like that. You certainly can't feel it moving or that its even there.

Not only did participants become more at ease with performing their exchanges, they also grew accustomed to performing exchanges in accordance to a schedule that suited them within the general guidelines they had to follow for the regimen. It was apparent that the regimen became a part of each individual's life as they no longer had to consciously remember to do exchanges. Participants grew so used to doing the exchanges that they became as much a part of life as eating and sleeping. It was obvious that a regimen that had started as very complex became easy to perform:

> It was kind of awkward. But I got used to it. I didn't mind. I don't mind it now. Its just like getting a cup of tea now.
>
> There's really not much to it. I'm getting used to it now. Its just a part of life.

In the beginning participants found that performing CAPD was a major disruption into their usual routines. They thought of CAPD as a nuisance as everyone was forced to interrupt activities and focus on performing their exchange. Even though the constant presence of CAPD in each individual's life did not change, it seemed that, for the most part, the regimen eventually fitted into the mainstream of everyone's day. For one participant sleeping in in the morning was only minimally interrupted by the CAPD schedule once she got used to it:

> You hook up the bags to your catheter and then after it is over I go back to sleep.

Over time the procedure did become familiar, in fact, it became second nature as the participants became accustomed to performing CAPD.

Being free: A paradoxical freedom

In view of the way participants spoke about the regimentation of their lives with CAPD it seems paradoxical that they would talk about the freedom that CAPD gave them. Yet all of the individuals who talked about their experiences discussed being free. A fifth theme was identified as 'Being free: A paradoxical freedom'. If we think about a paradox as something self-contradictory then even though CAPD imposed a number of restrictions and limitations on the participants, it also permitted freedom in other ways. Freedom for the participants was multidimensional as many of them found freedom in ways that only someone on dialysis could understand:

> Well, like I said, it gives you more freedom and you can go places and do what you like.

This statement was made despite the fact that the participant had described the restrictions of the treatment. In order to describe the kind of freedom CAPD allows

some of the participants contrasted it with being on hemodialysis. For individuals who had previously experienced hemodialysis, they valued CAPD for the control that it gave them over their lives. Even though they had to plan around a 6 hourly schedule, being free for the periods of time in between the performing of the procedure was a bonus for those who had only known what it was like to sit for 3 1/2 hours and receive hemodialysis:

> But its a different life. You can go wherever you want to; you can go into the woods; you can go out to the store. . . . So I certainly feel I can get around more.

For others just not having to go to the hospital to get hemodialysis three times a week for 3 1/2 hour periods was a major benefit of CAPD. When an individual had to make a trip to the hospital every second day and then stay there for up to four hours, it seemed that there was very little time left for any type of productive activity after going home. On days that hemodialysis was done they could plan very few other activities:

> Well, the other dialysis [hemodialysis] I was doing that three times a week. Well I had to be here to go to the hospital to get it done. Now with this one [CAPD] I can go anywhere I want to. So it doesn't tie me down.

Another form of personal freedom was the individual's ability to perform dialysis at home and according to a personal schedule. Participants did not feel as constrained doing dialysis in the privacy of their own home as they did by their commitment of going to a hospital for hemodialysis. Most of them felt that a 1/2 hour regimen four times a day allowed more freedom to do activities they enjoyed:

> So now that my hands are free, where say I got some work to do with my hands. Doing a quilt, or you know working with canvas or something like that. But I can now go ahead and do that. And the 1/2 hour doesn't be seeming that long.

Freedom for some related to how much better they felt physically on CAPD. Overall, most individuals were improved and did not have to recover from such problems as a drop in blood pressure after doing an exchange. All of them reported feeling physically and emotionally drained after receiving hemodialysis and they often had to go home and go to bed to recover from the ordeal. However, after CAPD most participants felt well enough to carry on with their usual activities:

> There's a big difference in my blood pressure and everything like that. You know, on the machine, I used to be knocked down every time.

Another form of freedom experienced was in the way that CAPD could be done almost anywhere. This applied not only to the home, but to any place that one could find to sit and do an exchange. Some reported going shopping and then retreating to the car just long enough to complete an exchange. Although many had a specific place in their house for doing dialysis, they were not restricted as to where they could perform the procedure in the house. Even if one could move only a short distance, it was viewed as an improvement over being forced to sit still in one place for 3 1/2 hours to receive hemodialysis:

> Now I mean sometimes when I'm washing and doing the dishes I might bring it all out with me . . . . you gotta keep moving your pole [I.V.] all the time. But you can do it.

The participants also found that CAPD allowed them greater opportunity to travel than when they were on hemodialysis. Although taking dialysis supplies along for a short trip was an inconvenience, most individuals did not mind this as they still had the option to go without having to make arrangements at other dialysis centres or they could go where there were no dialysis unit available. Even though they had to take travelling preparations into account, for the most part, as long as they took enough supplies along there was nothing else to worry about. Individuals found that they could travel longer distances by their ability to make arrangements to have

supplies delivered to any destination. Since they could carry the supplies they needed with them, participants did not have the added worry of locating a dialysis unit:

> But now I mean, if I wanted to go anywhere, I could. You know you got a lot of baggage to take, but you can go.

> I made arrangements before I went there [city] so that the solution was delivered out there [town]. So I made my exchanges out there. That's what you have to do if you're going anywhere for any period of time.

Individuals who had previously experienced hemodialysis also found that they had more freedom with what they could eat after starting on CAPD. Being able to eat or drink almost any kind of food or liquid in moderation was liberating, considering that with hemodialysis there were many things that were prohibited in their diets. Participants were not as conscious of regulating their intake and output on CAPD as when they were on hemodialysis:

> But when I was on hemodialysis I couldn't drink anything I wanted to. But when I started CAPD, I basically could eat and drink what I wanted.

Sharing the responsibility: Importance of a support person

Dialysis staff strongly recommend and encourage that a support person also learn how to perform CAPD with the person who will be going on dialysis. This person is then able to assist with procedures should assistance be required. Both the person learning CAPD as a self-care treatment and the support person attend instructional sessions and participate in the one-on-one teaching provided. A sixth theme that was identified was 'Sharing the responsibility: Importance of a support person'. Most of the participants indicated the presence of a support person and described their learning experience as a team effort:

> Well she [daughter-in-law] had to learn with me. But I do a lot of it myself now.

> The two of us went together and learned. But now I does it myself.

Participants also described the technical support that they received from their support person with their regimen once they went home. Most of the participants relied on the help given by family members when completing an exchange. Just having someone there to gather supplies together was an assistance they greatly appreciated. In many instances a spouse or partner either assisted with, or did, CAPD procedures:

> I would be in bed and he [husband] used to do it for me. He would hook me up.
>
> Now sometimes I might be too tired to walk up the stairs, so I might ask her [wife] to get me a bag of solution and warm it up in the microwave.

Knowing that someone was there to help them if a problem should arise was comforting for many of the participants. In many instances the assistance of another person was not always required, but knowing that they were not entirely alone with the responsibility of the regimen took an emotional burden off individuals. Even though the support person might never have to do the dialysis procedure, the knowledge that he/she was capable of doing it provided a sense of security:

> He [husband] did it to keep up with it. But now when I does it, he's usually there with me. But I handles everything. So if he had to do it for me, he could.

In some cases participants did not even have to order supplies or make telephone calls to the dialysis unit. Family members often assumed responsibility for ensuring that enough supplies were kept on hand and called the unit to discuss the condition of their loved one. Many participants were content with this arrangement

and felt confident that their support person knew as much about their condition as they did themselves. Not having to perform even those tasks helped lightened the responsibilities of those on dialysis:

> Because like we, my husband does all the ordering and ah . . . . looks out to the supplies in the house. Its a lot of worrying for him too.
>
> Yeah, she [wife] does all the talking to St. John's when she calls in to report. . . . . I know sometimes she's on there for a hour.

In one instance family members had assumed total responsibility for doing CAPD. This participant had relinquished total control of the performance of the regimen and allowed all the bag exchanges to be completed by two daughters. The daughters constructed a schedule for themselves that included doing alternating bag exchanges for their mother. This participant acknowledged that it was the team effort of her daughters that kept her alive and without their involvement her ability to live with the treatment was impossible:

> I have had all kinds of help. Like I said, she [daughter] took over. She does everything. I don't have a thing to worry about. I don't have to worry if there's ah . . . . dialysis ah . . . . bags there you know. I don't have to get

> medicine or worry about when I have to take my medicine. They [daughters] got it all laid out.

In another instance a support person was again vital for providing assistance with procedures the individual with CAPD could not perform. Having to prepare injections of antibiotics/heparin and keep daily records is intimidating enough for the average lay person, but for someone who cannot read or write, it is next to impossible. Without the assistance of the support person this participant's ability to maintain CAPD on her own would not have been possible. In order that this participant complete her regimen this support person came faithfully from next door every day and assisted with recording daily records and/or preparing injections of heparin:

> But she [daughter-in-law] handles the needles and the writing and that stuff. Things for my orders and that she does. Cause I can't read or write.

Many of the participants recognized that CAPD had affected the lives of everyone around them. Participants related how a significant other would take on additional responsibilities for many household duties. Since the person with CAPD had restrictions on weight bearing activities and could no longer carry out the responsibility for heavy chores, a family member was generally the one who carried the additional burdens:

> Like I say though, I have lots of help. He's [husband] so good. He's as good as a woman. And my daughter there, she takes over every now and then when she has no studying or nothing.

Other responsibilities were also shared. Besides providing physical support for chores, family members also carried a great deal of emotional strain. Participants felt that often family members suffered as much emotionally as they did themselves. Husbands and wives considered themselves a team and what affected one had an emotional impact on the other. Even though many of the participants felt badly over the additional burden shouldered by their spouse or partner, they also felt that if roles were reversed, emotional strain would also be reversed:

> Its been hard on my husband, girl, so hard. He's a worrier. He worries more about me than I do about myself. But of course if it was the other way I'd do the same thing.

> Sometimes the wife, she worries about me a lot too. But its no good to go worrying about it. I suppose it wouldn't be so bad if she didn't have to work.

In many instances participants talked of 'we' instead of 'I' when describing the effect of CAPD on their lives. Having someone to go through the experience with

seemed to make life easier. Individuals drew strength from knowing they did not have to bear their problems alone and recognized that without this support/encouragement they might not be able manage their responsibilities:

> And I mean, with the wife, she's a great help. Now it could be problems if I never had her. Her to help me out and everything. So between the two of us we can manage. . . . As long as you got an understanding woman. At least I got someone to share it with anyway.

Having easy access to a home dialysis unit by telephone was another source of support for these individuals. Knowing that information and help was available 24 hours a day by telephoning the dialysis staff, was a source of comfort. Individuals felt that even though they were responsible for their own care at home, dialysis staff were always available for them if ever they were needed. As a result, the participants did not feel alone, even though in some instances, they were geographically alone:

> If we didn't know how to do it [CAPD procedures], we could phone.
> I knows if anything is out of the way, all I got to do is call St. John's.

The Essence

Through an exploration of the experiences of CAPD with these eight individuals it was possible to broaden my understanding of the experience of living with CAPD. I was able to establish from the interviews the essence of the experience, or what made the experience what it was. I felt that the essence of the experience could be summarized as "gain in the shadow of loss".

Even though kidney disease caused a number of losses in these individuals' lives, CAPD was a gain. A diagnosis of ESRD meant that a person's life and future were threatened, but the availability of CAPD was a means for life to continue:

> At least this dialysis is keeping you alive, if nothing else.
>
> But I finds it kind of hard now. But I still guess I'm lucky just to be alive.

The nature of kidney failure and the losses incurred as a result formed the basis of meaning for living with CAPD. All participants described losses experienced as a result of kidney disease, how the disease had affected relationships, and the difficulties that they encountered as a result of loss of kidney function. It was difficult for participants to talk about treatment for renal failure without discussing the disease and the losses that accompanied the process. However, participants still saw CAPD as a gain, despite losses and changes that both the disease and treatment caused. For some,

they would be on dialysis as a method of renal replacement therapy for the rest of their lives and for others it was a way of buying time while awaiting kidney transplantation. Whatever the case, at some point CAPD allowed for continuation of life when the only other options were deteriorating health and eventual death:

> But like I say, if my health stays good you know and nothing else happens to me. I hope not. You know maybe I will have a transplant and have a good chance. Cause where I got no other problems, right and I don't need no other problems on top of what I got.
>
> Maybe things would be better if I could get a transplant done. But I know I'm not able to do that. Anyway, what would I want that for? I'm doing just as good with this [CAPD].

CAPD represented an additional gain for those who had previously experienced hemodialysis. Even though individuals had to perform their dialysis regimen every 6 hours, CAPD still allowed some degree of control. Individuals were permitted to follow a schedule that they adapted to the privacy of their own homes. Despite rigidity of the regimen, individuals could negotiate flexibility around the 6 hour schedule:

> Sometimes I skip my dialysis. I skip it, but its a couple of hours later in the morning before I do it.

> If I was invited out to supper, I would do the bag change at five instead of six.

Thirty minutes, four times a day was a small price to pay in comparison to the length of time and commitment required by hemodialysis. When performing CAPD individuals felt more in control than when they were on hemodialysis. One participant explained:

> Its a different life altogether. It only takes me ½ hour to do my dialysis [CAPD]. Whereas down there [hemodialysis unit] it would take me 3 ½ hours.

For others, CAPD meant that they could maintain some semblance of their usual life. Individuals living in rural areas did not have to move or travel to obtain dialysis. CAPD provided the means of staying at home to perform their dialysis treatment:

> I do like being home doing it [CAPD]. I don't have to be, well if I was on the other one [hemodialysis], I would have to move closer to the hospital. I wouldn't be able to stay home. I'd have to get an apartment down there. I'd

have to move say. So that's not very good. No, I'm satisfied with the way I'm going.

Its [hemodialysis] not something I would want to keep doing. I'd never be able to travel back and forth to the hospital.

Even though the participants experienced a number of routines, restrictions, changes, and commitments, they realized the benefits of CAPD and they spoke of it in terms of the gains they had while recognizing their losses.

CHAPTER 5

DISCUSSION

According to van Manen (1990) ". . . a true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance (p.32). Based on this, the following discussion will address themes identified in the study as they relate to previous literature and the understanding obtained from the findings by the researcher.

Discussion of Themes

This exploration into the experiences of living with CAPD, as it is understood from the patient's perspective, has broadened my understanding of what these individuals on this dialysis regimen confront on a day-to-day basis. Many of the studies in the literature, especially those on the stressors of dialysis, illustrate the negative aspects of the treatment regimen. The participants in this study certainly experienced stress and other negative consequences as a result of the demands of CAPD, and in exploring each individual's experience I obtained a greater appreciation of how these individuals view their world.

Analysis of the data demonstrates that on an emotional level individuals with ESRD using CAPD as their form of dialysis live with a great deal of uncertainty. They live with the uncertainty of their condition in that their health status can change quickly. Additionally they live with the uncertainty that CAPD will be able to sustain

their present level of health. Everyone realizes the importance of completing CAPD as instructed so that they might avoid further complications. In spite of the uncertainty each participant is able to maintain hope although the hope is tempered with caution. This theme is consistent with previous research that has found hope to be a necessity for helping individuals focus on positive outcomes (Baldree et al., 1982; Eichel, 1986; Hoothay et al., 1990; Rittman et al., 1993). Hoping things will get better with a kidney transplant, that the treatment will last indefinitely, or that an infection will not occur, are sources of hope that help these individuals maintain their optimism. It seems that the participants in this study, although cautious about what to expect, need to maintain hope in order to adapt to the illness and to have a life with value and meaning.

The individuals in this study are no different from individuals with other chronic illnesses - all human beings need hope to continue living (Forbes, 1994; Gaskins & Forte, 1995). For the participants the uncertainty of ESRD is partially held in abeyance with the availability of CAPD. It is this treatment that provides some hope for these individuals so they may have a positive outlook for their futures. Whether or not participants see a chance for a transplant or an indefinite lifetime on CAPD the treatment provides hope for a longer life. Even though the regimen has resulted in a number of changes in their lives individuals recognize that without this option their chances of living are definitely limited. The ability of these participants to maintain hope also confers with Rittman et al. (1993) in that the pain and disability

inflicted by renal failure is lessened by hope and provides a reason to struggle on in the face of doom and despair. Although most of the participants recognize that things could be worse, they remain cautiously optimistic that things will get better or remain the same.

Regimentation of life is another predominant theme as everyone describes how CAPD introduces new routines and restrictions into their lives. Although previous research acknowledges various restrictions imposed on an individual due to kidney failure and CAPD (Aoki & Muraoka, 1993; Beer, 1995; Eichel, 1986; Fuchs & Schreiber, 1988; Kline et al., 1985; Lindsay, 1982; Snavely, 1980), the way in which dialysis structures daily lives has not been addressed as fully. The necessity of planning events around dialysis times indicates how daily life becomes structured and different from the way that individuals usually live. Having to perform these complex procedures every 6 hours for an indefinite length of time makes the treatment a constant presence in the lives of the participants. Time and timing for these individuals takes on new significance as daily events are structured around the 6 hourly bag exchanges.

The participants also have to deal with the acceptance of a different self as they learn to adjust to the presence of the catheter and dialysate continuously being in their abdomen. As has been noted previously, patients with CAPD have to contend with changes in body image because of the fluid and catheter in the abdomen (Beer, 1995; Brey & Jarvis, 1983), but the extent of how these changes are experienced is limited.

These changes made the participants in this study redefine how they felt about themselves and how they have to live. Several of the participants find it difficult accepting the changes that CAPD has made to their bodies, and as a result do not view themselves as positively as they did before commencing dialysis. It seems that for these individuals their perceptions of their bodies have changed and they see themselves less positively. This finding is consistent with that of Beer who also found that individuals with CAPD experience difficulty with acceptance of change in self-concept. Like the individuals in Beer's study, these participant frequently mention their bloated abdomens and how the dialysate makes them feel "bigger". Whereas Beer did not report any differences between genders, the men and women in this study seem to exhibit different feelings about their body image. It appeared that the women were more concerned with a perceived altered body appearance than are the men. This theme, therefore, extends our knowledge of how individuals with CAPD might view themselves in relation to others, and how they feel others perceive them as different.

Individuals learn to integrate the CAPD regimen into their lives as indicated in the theme 'Familiar intrusions: Growing accustomed to the procedure'. It is difficult at first to get used to the complex routines, but eventually individuals grow accustomed to procedures and make them part of their normal routines. Although previous research on adaptation indicates that individuals with CAPD go through stages of adaptation (Brey & Jarvis, 1983; Gonsalves-Ebrahim, 1985; Mehall,

DeYoung, & DeYoung, 1981; Sorrels et al., 1982), and some types of personality characteristics are better suited for adaptation to the CAPD regimen than others (Borgeson, 1982; Gonsalves-Ebrahim et al., 1982; Whittaker, 1984), how these individuals perceive and incorporate events related to the treatment extends our present understanding of what it is like to live with this treatment regimen. Shurr et al. (1984) also found monotony of performing CAPD procedures a common complaint of individuals on the treatment, and even though the participants do not mention boredom with the regimen, several individuals say that having to do the same thing day after day "gets to them". This may be a reflection of monotony, although it is not labelled as such.

Due to the physical restraints imposed by the disease and treatment, several of the modified activities of the participants are consistent with those found by Jones and Preuett (1986). These activities indicate that individuals with CAPD learn to adjust to the demands of their treatment and modify lifestyles to fit regimen requirements. One participant states that to protect her peritoneal catheter she will hang small amounts of clothing on the clothes line to decrease the weight she has to carry. This action is a reflection of substitution as she finds ways to accommodate her new way of life. Another individual demonstrates withdrawal behaviour as she refuses to participate in activities that she once enjoyed. These individuals learn to live according to restrictions of the disease and regimen and adjust to not feeling as well physically as they did before kidney failure.

The individuals in this study are very knowledgable as a result of the education and training they receive `rom the peritoneal dialysis unit. The participants have successfully integrated the knowledge obtained in the education phase with everyday life. Everyone acknowledges that performing the regimen according to established guidelines is important and that their quality of life hinges on a willingness to cooperate with regimen requirements. Gurklis and Menke (1995) found that hemodialysis patients remain active by attending treatments, monitoring the body's response to treatment, taking medications, and recording symptoms of illness to health care providers. These activities are also demonstrated by participants in this study as everyone is actively involved in performing the treatment regimen every 6 hours. Individuals are always cautious that something may go wrong with their dialysis. The need to always inspect the drained dialysate and monitor the body's functioning through daily records of temperature, blood pressure, and weight, are, in some ways, synonymous with the theme guarding (Jones & Preuett, 1986) or monitoring the body's response to treatment (Gurklis & Menke). These activities aid participants in maintaining vigilance over their body, thus ensuring the best quality of self-care.

The fact that the participants in this study see an increase in freedom albeit a paradoxical kind of freedom as a result of being on CAPD, is consistent with literature that reports an increase in freedom and ability to travel with this type of dialysis (Oreopoulos & Khanna, 1982). Being free is now a multidimensional concept and covers a number of aspects of the participants' lives. This is especially so for those

who have previously experienced hemodialysis. Despite any routines and/or restrictions these individuals may experience, CAPD allows for more freedom in terms of ability to travel, what one can eat, and not having to go to the hospital for hemodialysis. The fact that participants see an increase in dietary freedom as a result of being on CAPD is also consistent with previous literature (Oreopoulos & Khanna). CAPD is an alternative that allows some flexibility and control in a disease that offers little flexibility or control. Even though one is required to perform the procedure there is a choice of when and where it can be done. Individuals are no longer restricted to hospitals and hemodialysis machines three times a week for three to four hours at a time. This theme again extends our understanding of CAPD as we now have a different perspective of what being free means for these individuals.

Some of the changes enforced by CAPD are similar to findings of Molzahn (1991). Many participants report lack of health, vigour, and freedom of action and time. Lack of health and vigour may be a consequence of kidney failure, but decreased freedom of action and free time for the participants are a result of the CAPD regimen. Attainment of health through CAPD affects attainment of other activities. Individuals in this study repeatedly report the difficulties of living their lives around the dialysis regimen. However, the losses, changes, and commitments are all small prices to pay, considering that without the availability of the treatment they would not live. All of them recognize that although they need to endure restrictions and changes, there is also a lot for which to be thankful. Life might have drastically changed, but CAPD

provides a means to an end - life itself.

As consistent with O'Brien (1990) the participants in this study also demonstrate reasoned compliance. Individuals learn to manipulate the system and adapt routines to better suit their needs. Even though everyone recognizes the importance of not skipping a dialysis treatment, they acknowledge that within routines there is flexibility with which one can work. Participants will not do anything to jeopardize their life and treatment regimen, but they do find ways of working around routines to better accommodate their lifestyle. This can be considered reasoned compliance as individuals debate the advantages and disadvantages of performing or skipping aspects of the treatment. This process seems to become easier as individuals grow accustomed to the regimen.

O'Brien (1990) also found secondary caregiver support to be more important than that of family and friends for influencing compliance with the hemodialysis treatment regimen. While this conclusion cannot be drawn from this study, findings do show that the participants value the support from the home dialysis unit. A shared responsibility for the treatment regimen for participants comes not only from family and friends, but also through telephone calls and visits with dialysis staff. The knowledge that help is always available from the dialysis staff provides comfort to individuals, especially those who live great distances from the centre.

Some participants become more dependent than others on outside assistance, and knowledge that help is available is something that they all value. Whether help

comes from spouses, significant others, or the home dialysis unit, having someone with whom to share the burden of responsibility helps lessen the burden of individuals. As consistent with previous literature (Christensen et al., 1992; Gonsalves-Ebrahim et al., 1982; Gurklis & Menke, 1995; Hume, 1984), the availability of social support does influence participants' abilities to cope with the CAPD regimen. Consistent with Snavely (1980) participants in this study also demonstrate that the more narrow conceptualization of self-care for CAPD is not always maintained as the involvement of a significant other in the regimen is a common practice. Having someone to go through the experience with and to share the burden of responsibility for care helps fulfil a physical, emotional, and psychosocial role, and is a source of security for alleviating the feeling of aloneness that one may feel when faced with the treatment regimen.

CHAPTER 6

LIMITATIONS, IMPLICATIONS, AND SUMMARY

This chapter includes an overview of the limitations of the study. Implications of the findings for nursing practice and nursing research are also identified as we become increasingly aware of the consequences that treatments to manage chronic disease and prolong life can have on people who maintain these self-care practices.

Limitations

One limitation of the study related to the ability of participants to articulate their experience. Even though all participants willingly shared their experience with the researcher, it was easier for some participants to express thoughts and feelings than others. For some it was not as easy to put into words exactly what they were thinking and feeling at particular points in time. Such was the case of the participant who could not read or write and felt that her ability to tell her story was affected by her education level. It was in instances like this that we do not know whether or not the findings of the study related to the natural verbal abilities of participants to express their experiences, the education level of participants, or the effects that kidney failure might have had on individuals' thought processes. Literature does support that one of the side effects of decreased kidney function is diminished cognitive function (Fennell et al., 1990), so we cannot exclude this as a possible factor influencing the findings in this research.

A second limitation was that the sample was comprised of participants who had been on CAPD for two years or less. Hence, differences in the lived experience of individuals living with CAPD for longer was unable to be assessed. We can only wonder whether perceptions change over time as individuals live longer and become more accustomed to the treatment regimen.

Thirdly, the findings of this study might have been influenced by limitations inherent in phenomenological research, such as a small number of participants. The number of participants in phenomenological research is typically small due to the large volume of verbal data that must be analysed (Sandelowski, 1986) and it is this restriction that might have limited the meaning of living with CAPD that was found in this study. While the phenomenological approach was useful in shedding light on living with CAPD, the overall findings were not sufficient to construct a definite meaning as to what it is like to live with this treatment for kidney failure. Even though in phenomenology "anyone's experience if well described, represents a slice of the lifeworld" (Sandelowski, p. 32), the investigation of only eight individuals' experiences might have failed to illuminate certain aspects of this experience. As a result of this restriction, another study that investigates the experiences of more individuals might shed further meaning as what it is like to be maintained on CAPD.

Implications

Nursing Practice

According to Rittman et al. (1993) nurses working with patients on dialysis are in a key position to witness and understand the effects of technology on the human mind, body, and spirit. Since CAPD is based extensively upon patient teaching of self-care practices, there are several implications for nursing practice regarding patient education. Nurses need to incorporate into their teaching sessions for patients on CAPD many of the themes identified in the study so that the patients may be prepared for some of the challenges that lie ahead for them. Patients need to be educated and have discussions about potential changes, restrictions, and commitments they may experience while on CAPD.

It would also be an important consideration to explore with individual patients their thoughts and feelings concerning the treatment regimen. Through one-on-one exploration of individual perceptions health care providers can obtain insight into how a person is coping with changes, restrictions, and/or commitments that the treatment might cause in an individual's life. Insight into how individuals incorporate the CAPD regimen into their lives may assist nurses when providing help to these individuals to better understand what is happening and if any changes can be made to enhance adjustment.

Nurses working with this group of individuals while stressing the importance of compliance can also recognize and empathize with the patient the restrictions and

responsibilities that the treatment entails. Since kidney failure has no cure, nurses have to place an increased emphasis on a caring role. "Genuine healing must be based on an authentic perception of the experience of illness of the individual person" (Rittman et al., 1993, p. 330). It is only through knowledge of the effects of CAPD on individuals' lives that nurses can help alleviate the effects of technology through the use of empathetic caring relationships.

Nursing practice can also be improved by educating nursing students on the physical, emotional, and psychosocial ramifications of the CAPD treatment regimen. Emphasis needs to be placed on the care for these patients rather than cure. There is no better place to start than with students who are open to new impressions and ideas.

Since maintaining hope was an underlying theme for living with CAPD, it is imperative that nurses find ways to foster hope in this group of individuals. According to Forbes (1994) the degree of hope a person possesses is dependent upon a caring relationship with significant others and health professionals. Since findings of this study illustrated the importance of a support person and hope when living with CAPD these areas need to be emphasized as nurses work to foster an improved morale for those with this treatment.

Additionally, during education sessions with individuals on CAPD nurses need to assess the amount and type of support that patients have at home with treatment regimens. Literature demonstrates the value of patient support groups for individuals sharing similar problems (Mock et al., 1994; Stewart, Kelly, Robinson, & Callender,

1995). Referrals to support groups are recommended for those having limited support services at home. This need can be met through a comphrensive nursing assessment completed during the initial training period. Patients need to be educated on the types of support services available so they can draw upon these services during times of need.

Nursing Research

Even though the number of individuals on hemodialysis is still far greater than the number of individuals on CAPD, statistics indicate that the population of individuals on CAPD is increasing (Fenton, 1996). Given this growing number of individuals on CAPD, the recent shift towards community based care, and the findings of this study, there is a need for future health care providers to take the initiative to expand knowledge about all aspects of living with the CAPD regimen. Each of the identified themes in this study needs to be explored further so that as more is learned about this method of renal replacement therapy, the care and understanding that is given to these individuals can continuously improve.

The findings of this study also indicate that research is needed in the area of understanding further the positive aspects of living with CAPD. Past research has mainly focused on the negative consequences of living with renal failure and dialysis and yet the results of this study demonstrated that there were positive aspects to being maintained on CAPD. Through gaining a better understanding of these positive

aspects nurses can focus on these areas when preparing individuals to manage their treatment.

Even though individuals from various age groups were represented in his study, future studies might also attempt to explore in greater depth the lived experience of different age groups of individuals with CAPD. This type of investigation might shed further understanding into how individuals of different ages perceive and deal with their experience. Individual needs change across the life span and what is important to individuals at one point in their life may have little relevance at another time. Besides telling us whether or not perceptions are consistent across all age groups, this awareness can also aid health care providers in determining what may or may not work for these individuals to live effectively with their treatment.

This study also identified aspects of living with CAPD that, even if noted in the nephrology literature, needs further investigation. Changes in body image, as related to the presence of the peritoneal catheter, has been addressed mainly from an editorial perspective. Further research into this area might attempt to gain an in-depth understanding of what it means for the person with CAPD to be subjected to modifications in body appearance. It is easy to say we know that changes occur to one's body image due to the dialysate and peritoneal catheter, but until we actually know what these changes mean to an individual it is difficult to effectively assist individuals with these changes. Attention has to be focused on the meaning of changes in body appearance so that individuals can be better equipped to deal with the

changes that may possibly confront them.

Since sharing the responsibility was also important for individuals with CAPD, it would be worthwhile to investigate the experience of living alone, or having very little support, with the CAPD treatment regimen. Not everyone has the benefit of having someone in their life who is willing to commit themselves to assist with a stringent regimen that also places restrictions on their lives. We are living in a time where people are living longer and not everyone will have someone on whom they can depend. Research needs to address what the experience is like for the person who assumes total responsibility for his/her CAPD regimen so that appropriate interventions might be available to assist these individuals. These participants described the involvement of their family members and how they felt their partners or children were affected by CAPD. As a contribution to the caregiving literature it would be helpful to study the caregivers and support people themselves and find out their perspectives on this important issue. How do caregivers experience CAPD and the kind of support they are asked to give? and "How are partners' or childrens' lives affected by having a close family member on CAPD?" are two questions we need to explore. Although a number of studies have assessed family coping, caregiving is not usually an aspect that has been studied (Flaherty & O'Brien, 1992; Srivastava, 1988). It is important not to conflate the two.

Future research might also attempt to address lived experience with the treatment regimen among groups of individuals on CAPD for various lengths of time.

This might increase understanding of whether perceptions change with time as individuals become more accustomed to living with the treatment regimen. We do not know whether an individual's ability to live with CAPD improves over time, or if they face the same concerns/problems over their lifetime. Therefore it is necessary that further research be conducted by way of a repeat study that uses a similar qualitative approach on a larger scale in order to find support for similar themes. While the generalizability of findings is not the aim of phenomenological research (Jasper, 1994), replication of the study to find support for similar findings would add credibility to these results.

Finally, it is also important that future research in this area look at the meaning of living with CAPD across different cultures. Since all the participants in this study were Caucasian we do not know if the experience is similar for individuals of various ethnic origins. It would be worthwhile to have an understanding of whether or not other cultural groups identify similar benefits and negative consequences of living with this treatment.

Summary

This study investigated the experience of individuals living with CAPD in Newfoundland. Six females and 2 male participants living with this method of renal replacement therapy participated in this phenomenological study by describing their experience. Six participants were interviewed twice and 2 participants were interviewed once. Each individual described many unique experiences related to this type of home dialysis on a day-to-day basis.

Analysis of the interview transcripts revealed six themes: (a) Maintaining hope: Cautioned optimism, (b) A different self: Presence of the catheter and dialysate, (c) The regimentation of life: Making an exchange every 6 hours, (d) Familiar intrusions: Growing accustomed to the procedure, (e) Being free: A paradoxical freedom, and (f) Sharing the responsibility: Importance of a support person. The essence of the experience was gain in the shadow of loss, as CAPD represented gain in the lives of individuals who had already lost a great deal through kidney failure. Following this, a discussion of the themes, in relation to the literature reviewed, was presented. Finally, limitations of the study and implications of the findings for nursing practice and research were discussed.

REFERENCES

Ahlmen, J. (1990). Quality of life: Views among patients on active treatment of uremia. *Scandinavian Journal of Urology and Nephrology, 131,* 43-46.

Aoki, K., & Muraoka, K. (1993). Analysis of continuous ambulatory peritoneal dialysis (CAPD) stressors in CAPD patients. *Kango-Kenkyu, 26,* 553-562.

Auer, J., Gokal, R., Stout, J. P., Hillier, V. F., Kincey, J., Simon, L. G., & Oliver, D. (1990). The Oxford-Manchester study of dialysis patients. *The Scandinavian Journal of Urology and Nephrology, Supplement, 131,* 31-37.

Baker, C., & Stern, P. (1993). Finding meaning in chronic illness as the key to self-care. *Canadian Journal of Nursing Research, 25*(2), 23-26.

Baldree, K., Murphy, S., & Powers, M. J. (1982). Stress identification and coping patterns in patients on hemodialysis. *Nursing Research, 31,* 107-112.

Beer, J. (1995). Body image of patients with ESRD and following renal transplantation. *British Journal of Nursing, 4,* 591-598.

Bihl, M. A., Ferrans, C., & Powers, M. J. (1988). Comparing stressors and quality of life of dialysis patients. *ANNA Journal, 15,* 27-37.

Borgeson, B. D. (1982). Continuous ambulatory peritoneal dialysis (CAPD): Some psychosocial observations. *Dialysis & Transplantation, 11,* 54-56.

Bremer, B. A., McCauley, C. R., Wrona, R. M., & Johnson, J. P. (1989). Quality of life in end-stage renal disease: A reexamination. *American Journal of Kidney Diseases, 13,* 200-207.

Brey, H., & Jarvis, J. (1983). Life change: Adjusting to continuous ambulatory peritoneal dialysis. *Health and Social Work, 8,* 203-209.

Bochenski, I. M. (1965). *The methods of contemporary thought.* Dordrecht-Holland: D. Riedel.

Brown, T. M., Feins, A., Parke, R. C., & Paulus, D. A. (1974). Living with long-term home dialysis. *Annals of Internal Medicine, 81,* 165-170.

Brunier, G. M., & McKeever, P. T. (1993). The impact of home dialysis on the family: Literature review. *ANNA Journal, 20,* 653-659.

Carosella, J. (1993). Reexperiencing loss: Diagnosis of end-stage renal disease in diabetic patients. *Dialysis & Transplantation, 22,* 722-733.

Chan, C. Y., & Greene, G. W. (1994). Dietary compliance among young hemodialysis patients. *Dialysis & Transplantation, 23,* 184-189.

Cheek, J. N. (1982). Patient feelings about illness: Do they affect compliance with the therapeutic regimen? *AANNT Journal, 10,* 17-20.

Cheng, E. (1992). Hemodialysis - a history: Evolution of a way of life (Part 3). *Dialysis & Transplantation, 21,* 71-79, 110.

Christensen, A. J., Smith, T. W., Turner, C. W., Holman, J. M., & Gregory, M. C. (1990). Type of hemodialysis and preference for behavioural involvement: Interactive effects on adherence in end-stage renal disease. *Health Psychology, 9,* 225-236.

Christensen, A. J., Smith, T. W., Turner, C. W., & Cundick, K. E. (1994). Patient adherence and adjustment in renal dialysis: A person x treatment interactive approach. *Journal of Behavioural Medicine, 17,* 549-566.

Christensen, A. J., Smith, T. W., Turner, C. W., Holman, J. M., Gregory, M. C., & Rich, M. A. (1992). Family support, physical impairment, and adherence in hemodialysis: An investigation of main and buffering effects. *Journal of Behavioural Medicine, 15,* 313-325.

Chubon, R. A. (1986). Quality of life and persons with end-stage renal disease. *Dialysis & Transplantation, 15,* 450-452.

Cummings, K., Becker, M., Kirscht, J., & Levin, N. (1982). Psychosocial factors affecting adherence in medical regimens in a group of hemodialysis patients. *Medical Care, 20,* 567-580.

DeVecchi, A. F., Scalamogna, A., Colombini, M., Cesana, B., Cancarini, G. C., Catizone, L., Cocchi, R., Lupo, A., Viglino, G., Salomone, M., Segoloni, G. P., & Giangrande, A. (1994). Well-being in patients on CAPD and hemodialysis. *International Journal of Artificial Organs, 17,* 473-477.

Eichel, C. (1986). Stress and coping in patients on CAPD compared to hemodialysis patients. *ANNA Journal, 13,* 9-13.

Evans, R. W., Manninen, D. L., Garrison, L. P., Hart, L. G., Blagg, C. R., Guttman, R. A., Hull, A. R., & Lowrie, E. G. (1985). The quality of life of patients with end-stage renal disease. *The New England Journal of Medicine, 312,* 553-559.

Everett, K. D., Sletten, C., Carmack, C., Brantley, P. J., Jones, G. N., & McKnight, G. (1993). Predicting noncompliance to fluid restrictions in hemodialysis patients. *Dialysis & Transplantation, 22,* 614-620.

Fennell, R. S., Fennell, E. B., Carter, R .L., Mings, E. L., Klausher, A. B., & Hurst, J. (1990). A longitudinal study of the cognitive function of children with renal failure. *Pediatric Nephrology, 4*(1), 11-15.

Fenton, S. S. A. (1996). Information from the facility profile questionnaires 1994 - Section 1. In: *Annual report 1996, volume 1: Dialysis and renal transplantation, Canadian organ replacement register.* Ottawa, ON: Canadian Institute for Health Information.

Flaherty, M. J., & O'Brien, M. E. (1992). Family styles of coping in end-stage renal disease. *ANNA Journal, 19,* 345-349.

Forbes, S. B. (1994). Hope: An essential human need in the elderly. *Journal of Gerontological Nursing, 20*(6), 5-10.

Fox, E., Peace, K., Neale, T. J., Morrison, R. B. I., Hatfield, P. J., & Mellsop, G. (1991). "Quality of life" for patients with end-stage renal failure. *Renal Failure, 13*(1), 31-35.

Fuchs, J., & Schreiber, M. (1988). Patients' perceptions of CAPD and hemodialysis stressors. *ANNA Journal, 15,* 282-286, 300.

Gaskins, S., & Forte, L. (1995). The meaning of hope: Implications for nursing practice and research. *Journal of Gerontological Nursing, 21*(3), 17-24.

Goeppinger, J., Arthur, M., Baglioni, A., Brunk, S., & Brunner, C. (1989). A reexamination of the effectiveness of self-care education for persons with arthritis. *Arthritis and Rheumatism, 32,* 706-716.

Gonsalves-Ebrahim, L. (1985). Psychological aspects of home care for the patient with end-stage renal disease. *Cleveland Clinic Quarterly, 52,* 299-302.

Gonsalves-Ebrahim, L., Gulledge, A. D., & Miga, S. (1982). Continuous ambulatory peritoneal dialysis: Psychological factors. *Psychosomatics, 23,* 944-949.

Gurklis, J. A., & Menke, E. M. (1995). Chronic hemodialysis patients' perceptions of stress, coping, and social support. *ANNA Journal, 22,* 381-390.

Hoffart, N. (1989). Nephrology nursing 1915-1970: A historical study of the integration of technology and care. *ANNA Journal, 16,* 169-178.

Hoothay, F., DeStefano, A. E., Leary, E. M., & Foley-Hartel, T. C. (1990). Life satisfaction and coping of diabetic hemodialysis patients. *ANNA Journal, 17,* 361-365.

Hume, M. R. (1984). Factors influencing dietary adherence as perceived by patients on long-term intermittent peritoneal dialysis. *Nursing Papers: Perspectives in Nursing, 16*(1), 38-54.

Hussey, L. C., & Gilliland, K. (1989). Compliance, low literacy, and locus of control. *Nursing Clinics of North America, 24,* 605-611.

Jasper, M. A. (1994). Issues in phenomenology for researchers of nursing. *Journal of Advanced Nursing, 19,* 309-314.

Jones, L., & Preuett, S. (1986). Self-care activities and processes used by hemodialysis patients. *ANNA Journal, 13,* 73-79.

Kelman, E. (1991). CAPD in Canada. *CANNT, 1*(3), 16-17.

Killingsworth, A. (1993). Psychosocial impact of end-stage renal disease. *British Journal of Nursing, 2,* 905-908.

Kline, S. A., Burton, H. J., Kaplan De-Nour, A., & Bolley, H. (1985). Patient self-assessment of stressors and adjustment to home hemodialysis and CAPD. *Peritoneal Dialysis Bulletin, 5,* 36-39.

Kutner, N. G, Brogan, D., & Kutner, M. (1986). End-stage renal disease treatment modality and patients' quality of life. *American Journal of Nephrology, 6,* 396-402.

Kyngas, H., & Hentinen, M. (1995). Meaning attached to compliance with self-care and conditions for compliance among young diabetics. *Journal of Advanced Nursing, 21,* 729-736.

Lancaster, L. E. (1988). Impact of chronic illness over the life span. *ANNA Journal, 15,* 164-168, 193.

Levenson, J. L., & Glocheski, S. (1991). Psychological factors affecting end-stage renal disease. *Psychosomatics, 32,* 382-389.

Lindsay, R. M. (1982). Adaptation to home dialysis: The use of hemodialysis and peritoneal dialysis. *American Association of Nephrology Nurses Technicians Journal, 9,* 49-51.

Markell, M., & Friedman, E. (1990). Care of the diabetic patient with end-stage renal disease. *Seminars in Nephrology, 10,* 274-286.

Martin, J. (1993). Peritoneal dialysis: Prescription for the 90's. *British Journal of Nursing, 2,* 162-166.

McLaughlin, J., & Zeeberg, I. (1993). Self-care and multiple sclerosis: A view from two cultures. *Social Science and Medicine, 37,* 315-329.

Mehall, D. L., DeYoung, K., & DeYoung, M. (1981). The psychological adjustment of a CAPD patient. *AANNT Journal, 8,* 23-24.

Mock, V., Burke, M. B., Sheehan, P., Creaton, E. M., Winningham, M. L., McKenney-Tedder, S., Schwager, L. P., & Liebman, M. (1994). A nursing rehabilitation program for women with breast cancer receiving adjuvant chemotherapy. *Oncology Nursing Forum, 21,* 899-907.

Molzahn, A. E. (1991). The reported quality of life of selected home-hemodialysis patients. *ANNA Journal, 18,* 173-181.

Moncrief, J., Popovich, R., & Nolph, K. (1990). The history and current status of continuous ambulatory peritoneal dialysis. *American Journal of Kidney Diseases, 16,* 579-584.

Muthny, F. A., & Koch, U. (1991). Quality of life of patients with end-stage renal failure. In: G. LaGreca, J. Olivares, M. Ferian, & J. Passlick-Deetjen (eds.). *CAPD- A decade of experience: Contributions to nephrology.* New York: Karger.

Nichols, K. A., & Springford, V. (1984). The psychosocial stressors associated with survival by dialysis. *Behavioural Research Therapy, 22,* 563-574.

Nissenson, A. R. (1994). Measuring, managing, and improving quality in the end-stage renal disease treatment setting: Peritoneal dialysis. *American Journal of Kidney Diseases, 24,* 368-375.

O'Brien, M. (1990). Compliance behaviour and long-term maintenance dialysis. *American Journal of Kidney Diseases, 15,* 209-214.

Orem, D. (1985). *Nursing: Concepts of practice* (3rd ed.). New York: Mcgrath-Hill.

Oreopoulos, D. G., & Khanna, R. (1982). The present and future role of continuous ambulatory peritoneal dialysis (CAPD). *American Journal of Kidney Diseases, 2,* 381-385.

Parker, J. (1983). Health locus of control: Implications for an end-stage renal disease program. *AANNT Journal, 10,* 29-35.

Perras, S., & Zappacosta, A. R. (1981). Identifying candidates for continuous ambulatory peritoneal dialysis. *Dialysis & Transplantation, 10,* 108-112.

Poll, I. B., & Kaplan De-Nour, A. (1980). Locus of control and adjustment to chronic hemodialysis. *Psychological Medicine, 10,* 153-157.

Pressly, K. B. (1995). Psychosocial characteristics of CAPD patients and the occurrence of infectious complications. *ANNA Journal, 22,* 563-574.

Prowant, B. F., Satalowich, R. J., Murray-Bell, A., Ryan, L. P., Schmidt, L. M., Kennedy, J. M., & Baker, B. L. (1989). Effectiveness of a phosphorus educational program for dialysis patients. *ANNA Journal, 16,* 353-357.

Rittman, M., Northsea, C., Haussauer, N., Green, G., & Swanson, L. (1993). Living with renal failure. *ANNA Journal, 20,* 327-331, 374.

Sandelowski, M. (1986). The problem of rigour in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Schlebusch, L., Botha, G. M., & Bosch, B. A. (1984). Coping styles in hemodialysis and continuous ambulatory peritoneal dialysis patients. *Dialysis & Transplantation, 13,* 517-521.

Schneider, M. S., Friend, R., Whitaker, P., & Wadhwa, N. K. (1991). Fluid noncompliance and symptomatology in end-stage renal disease: Cognitive and emotional variables. *Health Psychology, 10,* 209-215.

Sensky, T. (1993). Psychosomatic aspects of end-stage renal failure. *Psychotherapy and Psychosomatics, 59,* 56-68.

Sexton, D., & Munro, B. (1988). Living with chronic illness: The experience of women with chronic obstructive pulmonary disease (COPD). *Western Journal of Nursing Research, 10*(1), 26-44.

Shurr, M., Roy, C., & Atcherson, E. (1984). CAPD: Dialysis 365 days a year. *Journal of Nephrology Nursing, 1*(1), 20-24.

Simmons, R., & Abress, L. (1990). Quality of life issues for end-stage renal disease patients. *American Journal of Kidney Diseases, 15,* 201-208.

Simmons, R. G., Anderson, B. A., & Kamstra, B. A. (1984). Comparison of quality of life of patients on continuous ambulatory peritoneal dialysis, hemodialysis, and after transplantation. *American Journal of Kidney Diseases, 4,* 253-255.

Snavely, C. A. (1980). Patient independence in home peritoneal dialysis: One center's experience with self-care. *Dialysis & Transplantation, 9,* 1052-1054.

Sorrels, A. J., Mullins-Blackson, C., & Moncrief, J. W. (1982). Getting back to reality: Psychosocial adjustments to CAPD. *Nephrology Nurse, 4*(3), 22-23.

Srivastava, R. H. (1988). Coping strategies used by spouses of CAPD patients. *ANNA Journal, 15,* 174-179.

Stephenson, C. (1991). The concept of hope revisited for nursing. *Journal of Advanced Nursing, 16,* 1456-1467.

Stewart, A. M., Kelly, B., Robinson, J. D., & Callender, C. O. (1995). The Howard University Hospital transplant and dialysis support group: Twenty years and going strong. *International Journal of Group Psychotherapy, 45,* 471-488.

Swanson-Kauffman, K., & Schonwald, E. (1988). Phenomenology. In B. Sarter. *Paths to knowledge: Innovative research methods for nursing.* New York: National League for Nurses Publishing.

Tucker, C. M., Ziller, R. C., Smith, W. R., Mars, D. R., & Coons, M. P. (1991). Quality of life of patients on in-centre hemodialysis versus continuous ambulatory peritoneal dialysis. *Peritoneal Dialysis International, 11,* 341-346.

van Manen, M. (1990). *Researching lived experience.* London, Ontario: The Althouse Press.

Weed-Collins, M., & Hogan, R. (1989). Knowledge and health beliefs regarding phosphate-binding medication in predicting compliance. *ANNA Journal, 16,* 278-286.

Williams, A., Stephens, R., McKnight, T., & Dodd, S. (1991). Factors affecting adherence of end-stage renal disease patients to an exercise program. *British Journal of Sports Medicine, 25,* 90-93.

Whittaker, A. A. (1984). The influence of psychosocial factors on patient adjustment to continuous ambulatory peritoneal dialysis. *ANNA Journal, 11,* 10-16.

Wolcott, D. L., Maida, C. A., Diamond, R., & Nissesson, A. R. (1986). Treatment compliance in end-stage renal disease patients on dialysis. *American Journal of Nephrology, 6,* 329-338.

Wolcott, D. L., & Nissenson, A. R. (1988). Quality of life in chronic dialysis patients: A comparison of continuous ambulatory peritoneal dialysis (CAPD) and hemodialysis. *American Journal of Kidney Diseases, 11,* 402-412.

APPENDIX A

Approval from the Assistant Nursing Director of Medical Surgical Areas

GH
THE GENERAL HOSPITAL

300 Prince Philip Drive
St. John's, Nfld. Canada A1B 3V6

Health Sciences Centre
Telephone: (709) 737-6300
Fax: (709) 737-6400
Office: (709) 737-

Dr. L. A. Miller Centre
Telephone: (709) 737-
Fax: (709) 737-6969
Office: (709) 737-

October 16, 1995

Ms. Lisa Keeping
Graduate Student
Memorial University of Newfoundland
School of Nursing

Dear Lisa,

This is to confirm approval of your request to have the Peritoneal Dialysis Teaching Nursing to initially contact potential participants for your study of the experience of individuals receiving Continuous Ambulatory Peritoneal Dialysis. It is my understanding that following the initial contact, you will meet with the individuals concerned to obtain consent.

I wish you well with your study and look forward to hearing your results.

Sincerely,

Sharon Smith
Director of Nursing
Medical/Surgical Areas

cc: Cheryl Harding
Dialysis Department
SS/sh

APPENDIX B

Approval from the Medical Director of Peritoneal Dialysis

NEPHROLOGY CONSULTANTS

The General Hospital — Health Sciences Centre
St. John's, Nfld. A1B 3V6
Fax: 709-737-6995

Brendan J. Barrett, MB, M.Sc., MRCPI, FRCPC (709)737-5157
Assistant Professor of Medicine (Nephrology)

Patrick S. Parfrey, MD, MRCP, FRCPC, FACP (709) 737-7
Professor of Medicine (Nephrology)

John D. Harnett, MBBCh, FRCPI, FRCPC (709) 737-7179
Associate Professor of Medicine (Nephrology)

Michael D. Paul, MD, FRCPC (709) 737-6
Associate Professor of Medicine (Nephrology)

1995 10 05

Ms. Lisa Keeping, B.N., R.N.
39A Frecker Drive
St. John's, NF

Dear Ms. Keeping,

I have read through your proposal regarding the phenomenological research you are planning on 10 of our CAPD patients. I find no problem with your plans, and wish you well.

Yours sincerely,

Michael D. Paul, ~~MD~~, FRCPC
Co-ordinator
PD Unit

MDP/mc

c.c. Dr. J. Harnett
Home Dialysis Unit

APPENDIX C

Consent Form

School of Nursing

Memorial University of Newfoundland

St. John's, Newfoundland, A1V 3V6

Consent to Participate in Nursing Research

Title: Living With Continuous Ambulatory Peritoneal Dialysis

Investigator: Lisa M. Keeping BN.RN.
Telephone: 364-3723

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide to withdraw from the study at any time without affecting your normal treatment.

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available at all times during the study should you have any problems or questions about the study. The investigator's telephone number is provided on the last page of the consent form.

Purpose of the Study: The purpose of the study is to explore and describe the experience of individuals who have chosen continuous ambulatory peritoneal dialysis (CAPD) as their method of renal replacement therapy. By gaining an understanding of the experience, the quality of care provided to individuals with CAPD may be improved.

Description of Procedures: You will be asked to participate in one to three tape-recorded interviews, conducted at your home (or at a setting of your choosing). Initial interviews will last approximately 1 to 1.5 hours each. If clarification is needed another interview will be scheduled at a time which is convenient for you. In addition, you will be asked to read the investigator's written copy of your interview(s) to confirm that the description contained in the report adequately reflects your experience of living with CAPD.

Duration of Participation: Interviews for each person should be completed within a three month period.

Foreseeable Risks, Discomforts, or Inconveniences: There are no foreseeable physical risks as a result of the study. However, should you find it difficult to discuss private thoughts and/or emotions concerning your experience of living with CAPD then you can stop the interview at any time. You will be encouraged to talk to your

physician and/or other support systems already in place.

Benefits of Participation: You will have an opportunity to express your feelings and discuss your experience of living with CAPD with an interested, nonjudgemental listener. Some benefits of the study will not affect you directly but may affect other individuals who choose CAPD as their method of renal replacement therapy in the future.

Liability: Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator, sponsors, or involved institutions from their legal and professional responsibilities.

Any Other Relevant Information: If the study is not clear, please ask any questions before signing the consent form. If you have any questions or concerns about the study during or after interviewing is completed, please contact the investigator using the telephone number provided on the previous page, or alternatively my thesis supervisor Ms. Shirley Solberg, Memorial University of Newfoundland (737-6873). Study findings may be published and will respect the anonymity of all participants. Results will be available to all participants upon request.

I, _____, the undersigned, agree to my participation in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

_____ _____
(Signature of Participant) (Date)

_____ _____
(Witness Signature) (Date)

I, _____, the undersigned also agree to the audiotaping of the interviews which will be conducted as part of the research study.

_____ _____
(Signature of Participant) (Date)

_____ _____
(Witness Signature) (Date)

To be signed by the Investigator:

To the best of my ability I have fully explained to the subject the nature of this research study. I have invited questions and provided answers. I believe that the subject fully understands the implications and voluntary nature of the study.

_____
(Signature of Investigator)

APPENDIX D

Interview Guide

Interview Guide

Participants will be introduced to the interview session with the following dialogue:

I am interested in what it is like for you to live with continuous ambulatory peritoneal dialysis (CAPD). You can share any thoughts, feelings, and ideas you have regarding your experience of living at home with this type of dialysis. I would like for you to tell me in your own words what life on dialysis has been like for you. You are free to talk about whatever comes into your thoughts. I will assist you where I can, but only in asking questions to describe your experience as best as possible.

Examples of probes or clarifiers that may be used if needed (i.e. if participants are unsure where to begin, or need help to continue with their description):

1. Thinking back to when you were first told that you needed dialysis, can you tell me how you felt?

2. Can you describe the first time you had CAPD? What was it like?

3. Have you had to make changes in your life since you started receiving CAPD? What are some of these?

4. What have been the advantages of CAPD for you?

5. What are the disadvantages of CAPD for you?

6. If anyone told you they were to start CAPD, based on your experiences, what would you tell them?

7. Would you describe a typical day in your life?

8. Are there any other thoughts or comments that you would like to add to your experience of living with CAPD?

APPENDIX E

Approval from Human Investigation Committee

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine, The Health Sciences Centre

October 24, 1995

TO: Ms. Lisa Keeping

FROM: Dr. F. Moody-Corbett, Acting Assistant Dean,
Research and Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee #95.123

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled **"Living With Continuous Ambulatory Peritoneal Dialysis".**

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

It will be **your responsibility to seek necessary approval from the hospital(s) wherein the investigation will be conducted**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

F. Moody-Corbett, Ph.D.
Acting Assistant Dean

cc Dr. K.M.W. Keough, Vice-President (Research)
Dr. Ford Bursey, General Hospital Representative, HIC
Dr. Eric Parsons, Medical Director, General Hospital

APPENDIX F

Approval from Health Care Corporation

Health Care Corporation of St. John's
South Wing, Waterford Hospital, Waterford Bridge Road,
St. John's, NF Can. A1E 4J8

1995 11 16

TO: *Ms. Lisa Keeping, Masters of Nsg. Candidate*

FROM: *Eric R. Parsons, MD,CCFP,*

SUBJECT: **#95-123 - Living With Continuous Ambulatory Peritoneal Dialysis.**

This letter is to formally inform you that the Board of Directors of the Health Care Corporation of St. John's has recently approved your above investigation on recommendation of the Medical Advisory Committee at the General Hospital.

The approval to conduct this research is contingent on the preparations of formal budgets and when the investigation is being done on the request of a pharmaceutical company and others where responsibility and ownership of the data is their's, indirect costs (overhead) will be charged. You will be contacted in the near future by a representative of the hospital or university for review of your budgets and possible assessment.

ERIC R. PARSONS, MD,CCFP,
Vice-President,
Medical Services

ERP/sh
c.c. Linda Purchase,Research Centre
Site Administrator, The General Hospital

Tel (709) 364-3901 Fax (709) 364-3903

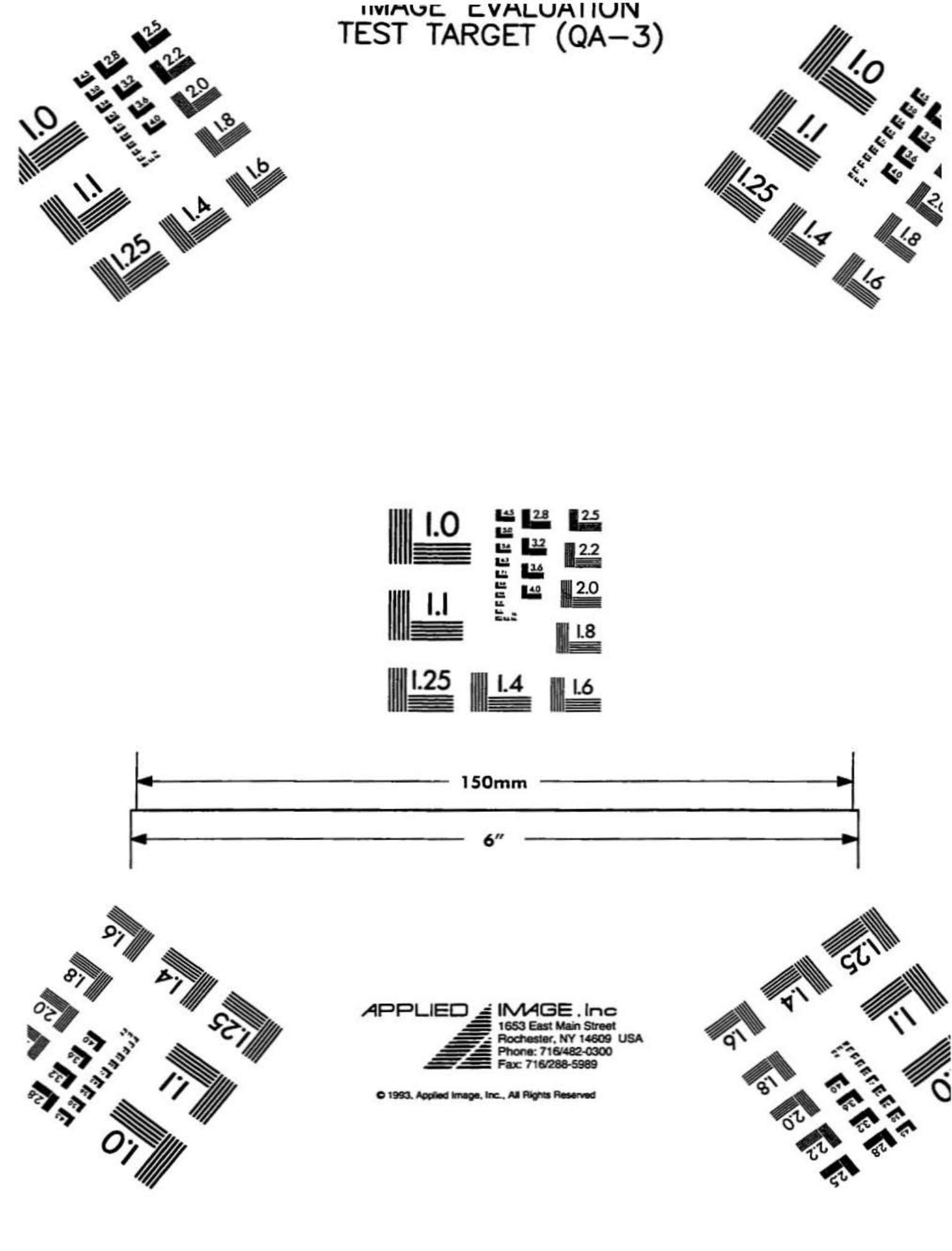
IMAGE EVALUATION
TEST TARGET (QA-3)
1.0
1.1
1.25
1.4
1.6
1.8
2.0
2.2
2.5
2.8
3.2
3.6
4.0
150mm
6"
APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989
© 1993, Applied Image, Inc., All Rights Reserved